

**A STUDY INTO PALLIATIVE CARE SERVICES FOR  
OFFENDERS WITH AIDS AT  
WESTVILLE PRISON**

**BY**

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for the degree of**

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**In the Department of Social Work in the Faculty of  
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## **DECLARATION**

**I, Aneetha Devi Moodley, hereby declare that this  
dissertation**

**“A STUDY INTO PALLIATIVE CARE SERVICES FOR  
OFFENDERS WITH AIDS AT WESTVILLE PRISON”**

**is the result of my own work, except as indicated in the text  
by references and quotations. My supervisor has guided  
me with suggestions for refinement.**

A handwritten signature in cursive script, appearing to read 'A. D. Moodley', written over a dotted line.

**A. D MOODLEY**

## **ABSTRACT**

The study sought to determine what palliative care services were provided to offenders at Medium B correctional center, which is located at Durban Management Area. It identified the perceptions of offender-patients about the services they received. The study also identified challenges that staff and offender-volunteer caregivers faced in rendering services within a correctional context in South Africa.

The sample consisted of three stakeholders, namely, offender-patients who were terminally ill with AIDS at the prison hospital, staff and offender volunteer caregivers.

The methods of data collection comprised of content analysis, semi-structured interviews with offender-patients and focus group discussions with staff and offender volunteer caregivers.

The study revealed that efforts were made by the Department of Correctional Services to provide services to terminally ill AIDS patients. Legislation and policy frameworks were consistently being developed by the Department to meet the needs of patients and to keep abreast with international best practices.

Some services were in accordance with the theoretical framework of palliative care. However, many challenges were experienced because of the contextual constraints in which the services were being rendered.

Recommendations to improve the delivery of services were made by all participants in the study. The study concludes with the recommendations by the researcher and suggestions for future research.

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## FOREWORD

Palliative care in HIV must be able to adapt to the fluctuating yet ultimately downward course of the HIV disease. The central role of medication adherence is important, but other factors can be equally important to optimizing clinical outcomes. These factors include socioeconomic factors as well as personal characteristics: an understanding of the disease process; empowerment in relation to personal health; a safe place to live; freedom from pain and distressing symptoms; adequate nutrition; treatment for substance abuse, depression and other mental illness; hope; adequate help of family, friends and other caregivers, especially when functional status is diminished and disease progression is ongoing. These challenges can be met successfully by using a palliative care framework to approach the patient, providers, caregivers, family, loved ones and the health care system.

O'Neill, Selwyn et al: 2003

These challenges are, however, intensified when care is provided to offenders within the context of corrections.

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# CHAPTER ONE

## 1.INTRODUCTION AND METHODOLOGY

### 1.1 Introduction

The provision of palliative care services for patients with Acquired Immunodeficiency Syndrome (hereafter referred to as AIDS) is becoming critical. During 2003, three million people died of AIDS related illnesses globally, which translates to 8219 deaths per day (UNAIDS, 2003:2). According to Mhlophe (2005:18) more than 340 000 South Africans died of AIDS-related diseases between 2004 and 2005.

Prisons are experiencing a similar situation. The Judicial Inspectorate of Prisons (Fagan, 2002:16) reported that there has been an increase in the number of natural deaths in South African prisons, and that these natural deaths appear to be mostly caused by HIV and AIDS. Fagan (2003:1) anticipated that given the extent of the AIDS pandemic there will be a continued escalation in natural deaths at the rate of about 34% per annum in prisons. This will mean that about 15 000 prisoners will die in the next five years and in ten years from now the deaths could amount to about 35 000 and more per year from a total of approximately 186 000 offenders. The Department of Correctional Services is now being confronted with dealing with an increasing number of offenders who are terminally ill with Aids and are in need of palliative care services. This study undertook to investigate the palliative care services for offenders with Aids at Durban Management Area.

## **1.2 Research Problem**

Prisons in South Africa have to deal with an increasing number of offender-patients who are terminally ill with AIDS and are in need of care. They are under pressure by the World Health Organization's guidelines (WHO/GPA/DIR/93.3) to ensure that the services they provide are equivalent to those available to communities. In South Africa several community organizations, notably the hospice movement, is advocating the provision of palliative care services to AIDS patients in communities. The Department of Health's policy guidelines are also advocating the same (Mamopi Consultants & Associates, 2002:24). The provision of palliative care services to terminally ill offenders is also an international trend (Thigpen & Hunter, 1998:1). The Department of Correctional Services is striving to provide palliative care services to prisoners with HIV/AIDS. However the provision of palliative care services within a correctional setting is complex and challenging.

This research was conducted to ascertain what palliative care services were available to offenders who were ill with AIDS at Medium B Correctional Center, Durban Management Area. The study also looked at the perceptions of the offender-patients about the palliative care services they received, and the challenges that staff faced in the rendering of palliative care services within a correctional context. Finally, the study determined the recommendations of the staff and offenders for the improvement of palliative care services within the prison.

### **1.3 Motivation And Value Of The Study**

The researcher, as a manager at the Department of Correctional Services, was motivated to conduct this study because of the steadily increasing number of AIDS patients now reaching the terminal stage of the illness. There were major concerns about the provision of adequate palliative care services to terminally ill offender-patients. This study was therefore an attempt at being pro-active in the face of a growing problem.

Many policies have been adopted by the Department of Correctional Services, which deals with the service provision to offender-patients who are terminally ill with AIDS. The results of this study may influence new policies and practices based on the opinion of the main role-players, the recipients of the services and the service providers who have to ensure adequate care services within the constraints of the correctional environment.

It is envisaged that the study will also result in improvements in correctional centre-based care for the dying offender-patient, thus enabling them to die with dignity.

The study will be of value to the offenders and various practitioners involved in the delivery of palliative services to offenders. It should also be of interest to human rights activists and policy makers.

### **1.4 Aims And Objectives Of The Study**

- To ascertain what palliative care services are available for offenders who are ill with AIDS at Medium B Correctional Center, Durban Management Area.
- To assist with the formulation of more focused policy, concerning the provision of palliative care services to offenders who are ill with AIDS and are possibly dying.

- To make a contribution to the professional body of knowledge on how to improve palliative care services to offenders, as this is an under-researched area.

## **1.5 KEY QUESTIONS**

- What palliative care services are available for offender-patients who are terminally ill with AIDS at Durban Management Area?
- What are the perceptions of the offender-patients about the palliative care services that they receive?
- What challenges are encountered in the rendering of palliative care services?
- What are the recommendations of the staff and the offenders to improve the palliative care services?

## **1.6 LEGISLATIVE AND POLICY CONTEXT OF THE STUDY**

The study was undertaken at Medium B Correctional Centre, one of forty two correctional centres in KwaZulu-Natal. Medium B Correctional Center is situated at Durban Management Area. This correctional facility is classified as a large maximum security facility in terms of the classification of the Department of Correctional Services. It has a prison hospital, which provides for both primary health care as well as in-patient treatment. This hospital provides a twenty-four hour health care service.

Prisoners are sentenced under the Criminal Procedure Act (Act No 51, 1977). The Correctional Services Act, (Act No 111, 1998) regulates the incarceration of offenders and has many stipulations, which might impact on the provision of palliative care services.

In South Africa the Bill of Rights as enshrined in Chapter 2 of the Constitution of the Republic of South Africa, Act 108 of 1996 ensures the offenders rights to confidentiality, healthcare, dignity and to an environment that is not harmful to their health and well-being. The Department of Correctional Services has internal policies which guides service delivery. Chapter 3 of the Correctional Services B-Order deals with the provision of health care to offenders within correctional facilities. According to Section 37 of Chapter 3 of the B-Order, "the prison health service must provide a service for the diagnosis, assessment, treatment and care of prisoners with HIV/AIDS and those with HIV related diseases." The Department of Correctional Services also follows the World Health Organization's Guidelines for the Management of HIV/AIDS in prisons.

According to the World Health Organization's equivalence rule with states that whatever health care and prevention is available to the community at large should also be available to the incarcerated community (WHO/GPA/DIR/93.3). In South Africa the Department of Health is advocating the provision of palliative care services to patients who are terminally ill via a home based care system (Mamopi Consultants and Associates, 2002:24). The Department of Correctional Services is attempting to replicate this policy in prisons. This is reflected in section 38.2 of the B-Order. The following principles are contained in the policy guidelines (B-Order, S.38.2) and are applicable to palliative care:

- The right to a healthy and safe environment conducive to care
- Access to health care
- Confidentiality and privacy
- Informed consent of the patient
- Referral for a second opinion
- Exercise choice in health care
- Continuity of care
- Participation in decision making that affects his/her health
- Be treated by a named health care provider
- Right to refuse treatment
- Right to complain about the health care service they receive should it be necessary.

A further attempt to achieve equality of services with those in the community and to facilitate the provision of palliative care is evident in the Draft Policy on Correctional Centre Based Care for Terminally Ill Patients. It is an adapted form of the home-based care system using volunteer caregivers. Based on this practice this draft policy makes provision for the use of offenders as volunteers to care for offender patients who are terminally ill and need palliative care. It makes provision for selection and training of the volunteers, determines their scope of work, gratuity they will receive, ratio of care-giver to patient (1: 5), and care for the caregivers.

Thus the Department of Correctional Services has made efforts to constantly review and develop policies to meet the needs of prisoners and to meet international standards.

## **1.7 THEORETICAL FRAMEWORK OF THE STUDY**

The treatment and care model (Avert.Org:2004) was used as the theoretical framework of this study. It outlines the various stages in the progression of HIV and AIDS from the point of diagnosis to bereavement. It proposes a continuum of care and clearly highlights the various types of services that are predominately required at the various stages of the illness. The need for palliative care becomes more intense as the disease progresses to the terminal phase. It was chosen as it is compatible with palliative care theory and will be elaborated on later in the literature review (Chapter 2, Page 35). The themes of the data collected were based on this model.

## **1.8 RESEARCH METHODOLOGY**

### **1.8.1 Selection Of A Design**

Mouton (cited in De Vos and Strydom et al, 2002: 137) defined a research design as a plan of how one intends conducting the research. Rubin and Babbie (cited in De Vos and Strydom et al, 2002:138) further stated that the research design referred to all the decisions a researcher makes in planning the study, that is, decisions about the overall design to use, about sampling sources and procedures for collecting data, measurement issues, and data analysis plans.

According to De Vos and Strydom et al (2002:109) "descriptive research presents a picture of the specific details of a situation, social setting or relationship, and focuses on "how" and "why" questions. This study intended to capture this kind of information with regard to the provision of palliative care services at Durban Management Area. Thus a descriptive design was considered appropriate to meet the objectives of the study.

### **1.8.2 Sampling Method**

A sample comprises the elements of the population considered for actual inclusion in the study, or it could be a small portion of the total set of objects, events or persons that together comprise the subject of our study (De Vos & Strydom et al, 2002:199). The sample in this research was drawn from the offender and staff population at Medium B Correctional Centre, at Durban Management Area.

According to Rubin and Babbie (1997:237) two types of sampling methods exist, namely probability and non-probability sampling. Sarantakos (cited in De Vos & Strydom et al, 2000:156) is of the opinion that in qualitative investigations non-probability sampling is used almost without exception. Since the main focus of this study was qualitative in nature, non-probability sampling was considered appropriate.



Sarantakos (cited in De Vos & Strydom et al, 2000:156), described sampling in qualitative research as relatively limited, based on saturation, not representative, the size not statistically determined, involving low cost and access to the sample not being time consuming. These factors were considered when deciding on the sample in this research.

The sample comprised of three different target groups:

### **Sample One : Offender-Patients**

The sample size depended on the number of offender-patients who were terminally ill with AIDS in the prison hospital at the time of the data collection stage of the study. They had to be physically, emotionally and psychologically well enough to be included in the study as determined by the nursing staff who were in daily contact with them. Seven male sentenced offender-patients met the above criteria. Although, theoretically, palliative care services start at diagnosis, it was decided that the sample should comprise of terminally ill patients at the prison hospital only, as data could be collected to illustrate the full progression of illness and the care services received at the various stages. The sample was also easily accessible.

### **Sample Two : Focus Group of Staff**

Participants are selected because they have certain characteristics in common that relate to the topic of the focus group (De Vos & Strydom et al, 2002:305). The sample was drawn from the various staff groups providing services to AIDS patients within the prison. At the time of the study some of them were providing limited or no services to terminally ill patients at the hospital, but had provided services to HIV-positive offenders in the general offender population. They had thus provided services to offenders at the initial stages of the illness and therefore had a good knowledge of the constraints of providing palliative care services within a correctional setting.

It was decided to include them in the sample as they were considered to be significant to the study by the offender-patients interviewed and by the integrated team model in palliative care (Chapter 2, Page 50). The following members of staff were included in the focus group:

- Nurse
- Social Worker
- Psychologist
- Chaplain
- Custodial Official

The doctor was unfortunately not available to attend the focus group discussion.

### **Sample Three : Focus Group of Offender-Volunteers**

The researcher had not planned to include this sample in the study. However, during the interviews with offender-patients and staff it had become apparent that offender volunteers were providing palliative care services to offender-patients and were important to the study. Because of the qualitative nature of the study, which allows sampling to be undertaken after the actual investigation has commenced (De Vos & Strydom et al, 2002:333), the researcher decided to include them in the study. Five members of the executive committee of the offender organization called the AIDS Control Committee, who work as offender-volunteer caregivers, were part of the focus group interviews.

## **1.9 Methods Of Data Collection**

The study used a combination of quantitative and qualitative data- collection methods. The quantitative method of data collection focused on the demographic and factual information that were gathered from the files of offender-patients who were ill with AIDS and admitted to the prison hospital at Durban Management Area.

Babbie (1997:160) defined qualitative research as the style of research used to describe, interpret or reconstruct the subjectively meaningful worlds of people. The essence of the qualitative approach is to view events through the perspective of the people being studied, the way they think and view the world. This was the intention of the study.

The following data collection methods were used:

### **1.9.1 Content Analysis**

Content Analysis is described as a quantitative data collection technique used for examining information or content and is used most often in descriptive research (Neuman in De Vos & Strydom et al, 2003: 322). Some authors also describe this method of data collection as the record method (Bless & Higson-Smith, 2000:125). The researcher perused the offender-patients' institutional files and medical files, which also contained social work reports for the purposes of medical releases. This was done in order to obtain information of what palliative care services were available to the offender-patients. This also allowed the researcher to trail the services provided from diagnosis to bereavement since the continuum of care is an important component of the treatment and care model, which forms the theoretical framework of this study. The use of content analysis also served the purpose of creating objectivity by validating the information that was received from the staff. It also limited the challenges around the receiving of information from staff that may be provided for the purposes of impressing the researcher. Obtaining information from records also served the purpose of minimizing the burden on the offender-patients to provide this information.

Information on the following broad themes were obtained from the files:

- Demographic information
- Progression of disease:
  - Diagnosis
  - Number of admissions to the prison hospital
  - Discharge planning
- Overview of services provided by caregivers
- Type of specialist care referrals
- The support networks of offenders

### **1.9.2 Semi-structured Interviews With Offender-Patients**

Generally semi-structured interviews are used to gain a detailed picture of a participant's belief about, or perceptions of, a particular topic (De Vos & Strydom et al, 2002:302). In this study semi-structured interviews allowed the researcher enough freedom to probe the perceptions of the offender-patients about the palliative care services that they received.

The researcher initially visited the hospital to observe the general functioning at the hospital and to meet with staff and offender-patients to explain about the proposed research and obtain consent from the offender-patients who were able to and wanted to participate. This visit also served the purpose of building rapport with the patients and staff and to make them feel comfortable and at ease with the researcher. These are important factors when collecting qualitative data according to De Vos & Strydom et al (2002:303).

The interviews with the offender- patients were conducted during a single session. However, if the physical and emotional states of the patients were such that they could not withstand a single interview session, they would have been conducted over two or three sessions of shorter duration.

The services of an interpreter were used with one research participant only. The interpreter was trained in ethical issues, on the nature and sequence of questions and on the need to maintain confidentiality.

The researcher intended referring respondents to social workers at the prison if the interviews had evoked strong emotional reactions from the offender-patients about their illness, fear about dying or concerns about family. There was, however, no need for such referrals during or after the interviews.

The following broad themes were covered during the interviews:

- Services and support received
- Perception about the quality of service
- Resources and support available
- Recommendations

### **1.9.3 Focus Group Interviews with Staff**

Once all the interviews with the offender-patients were concluded a focus group discussion was conducted with staff. Focus groups are a means of better understanding how people think or feel about an issue, product or service.

The focus group discussion was guided by information that was obtained from the offender-patients and by reviewing of existing policy.

The following themes were discussed:

- Services provided
- Strengths and challenges in providing palliative care services in terms of:
  - Policy
  - Infrastructure
  - Resources
  - Support networks and services
  - Teamwork
  - Planned management of care
- Recommendations on improvement

#### **1.9.4 Focus Group Interviews With Offender-Volunteer Caregivers**

After the focus group interview with the staff a focus group was conducted with five members of the offender organization called the AIDS Control Committee, who offered voluntary palliative care and other services to offender-patients. The broad themes that were covered are similar to the group discussion with staff, namely:

- Services provided
- Constraints experienced in rendering these services
- Recommendations for improvements

It was considered important to use triangulation for data-collection in this study. Triangulation is using multiple methods to provide insights into the same events or relationships (De Vos & Strydom et al, 2002: 341). Use of multiple methods of data-collection is particularly important in situations where power differences exist, as in prisons, and the respondents might be reluctant to answer honestly. This ensured that the results were more reliable and valid.

## 1.10 SUMMARY OF DATA COLLECTION METHODS

Table 1: Summary of Data Collection Methods

<b>DATA COLLECTION METHOD</b>	<b><u>PURPOSE</u></b>	<b><u>SAMPLE</u></b>
1. Content Analysis	<ul style="list-style-type: none"> <li>- To get an overall view of services that were provided during the progression of the illness.</li> <li>- Sample characteristics and demographic information</li> </ul>	Seven case records of offender-patients who were interviewed for purposes of the study
2. Semi-structured Interviews	<ul style="list-style-type: none"> <li>-To determine the perceptions pertaining to the quality of services</li> <li>- To obtain recommendations</li> </ul>	Seven offender-patients who were terminally ill with AIDS and admitted to the prison hospital at the time of the study
3 Focus Group Discussion: Staff	<ul style="list-style-type: none"> <li>- To get an overall view of services that were provided during the progression of the illness.</li> <li>- To determine challenges being experienced</li> <li>- To obtain recommendations</li> </ul>	<p>A representative from each of the following disciplines who worked/should work with the offender-patients at the hospital:</p> <ul style="list-style-type: none"> <li>• Nursing</li> <li>• Social Work</li> <li>• Psychology</li> <li>• Chaplain</li> <li>• Custodial Official</li> </ul>
4. Focus Group Discussion: Offender Volunteer Caregivers	<ul style="list-style-type: none"> <li>-To determine the palliative care services that are currently being provided</li> <li>- To determine what challenges are being experienced in the rendering of these services</li> <li>- To obtain recommendations to improve on the existing situation</li> </ul>	Five members of the AIDS Control Committee (offender organization)

## **1.11 DATA ANALYSIS**

All the data collected and observations made were recorded by means of detailed process notes. The issue of tape recording was considered, but after deliberation with the prison staff and offenders, it was not pursued as it was felt that the respondents would feel intimidated by the equipment. The impressions of the interviews were noted immediately after the completion of the interviews. The responses of the research participants were thereafter processed into different themes and analyzed. After analysis the data was depicted using tables, direct quotations and direct transcripts from records where appropriate.

## **1.12 LIMITATIONS OF THE STUDY**

There were several limitations to the study, namely:

- The researcher is English speaking and was compelled to utilize the services of an interpreter for one interview. The result could be that some information may be lost during the interpretation process and that confidentiality could have been compromised.
- The medical practitioner, a key member of the palliative care team, was not available to attend the focus group discussion with staff.
- The researcher is employed in a managerial capacity at the Provincial Office of the Department of Correctional Services. As such colleagues and offender-patients may have wanted to provide an “ideal” scenario, rather than depict the situation as is, in an effort to impress.



## 1.13 ETHICAL CONSIDERATIONS

Research with persons who are dying is particularly challenging and can be controversial. They are a vulnerable population in a situation complicated by physical decline and often debilitating symptoms of discomfort and distress. The situation is further complicated by the emotional intensity inherent in the knowledge of impending death (Dean & McClement, 2002:376).

However, Beaver & Luker et al (1999:13) stated that the potential benefits to vulnerable persons of being involved in such research might not be immediately obvious. They are of the view that the respondent might believe that his contribution will help others and this sense of altruism will indirectly benefit him. Telling one's story might also be therapeutic for some.

It must be noted that the decision to include terminally ill offenders in the study was taken after deliberation on ethical considerations. The researcher nevertheless considered it necessary to interview offender-patients' as these interviews would probably elicit valuable information. It was felt that hearing the voices of the recipients of services would enhance the value of the study.

In undertaking this research the following are some of the methodological and ethical issues that were considered because of the sensitive nature of the study:

- Energy depletion: As terminally ill patients often lack energy to actively participate in research, the interviews were of relatively short duration and concluded within forty-five minutes.
- Attrition: Researchers who work with the dying are inevitably confronted by attrition in participant numbers. Should this happen the researcher should not be discouraged from continuing.

- **Benefits and risks:** There should be an understandable explanation of risks and benefits, although palliative care patients in the terminal stages of the disease are unlikely to personally benefit from the research.
- **Informed Consent:** Informed consent is necessary even though the patient may frequently experience changes in cognition. In this study it was not necessary to apply process consent whereby consent is renegotiated as time passes and circumstances change.

All participants, that is, offenders and staff, completed consent forms prior to commencement of the interviews; copies are attached as appendix “A”, “B” and “C” respectively.

- **Emotional burden:** Interviews may raise issues such as terminal illness, suffering and loss. The researcher needed to be prepared to postpone or even forego the research agenda in favor of responding with sensitivity and compassion when emotional distress is experienced. It was the researcher’s intention to refer such cases to the prison social workers. It was, however, not necessary to refer any of the research participants to social workers as a result of emotional distress during the interviews.

The research proposal was approved by both the Ethics Committees at the Department of Correctional Services and the University of KwaZulu Natal prior to commencement of the study.

## 1.14 KEY CONCEPTS

Hereunder are the definitions of the key concepts considered central to this study:

***Palliative care:*** is described as care, which aims to achieve the best quality of life for patients suffering from life threatening and incurable illness, including HIV and AIDS. Crucial elements are the relief of all pain, that is, physical, psychological, spiritual and social pain. It also looks at enabling and supporting caregivers to work through their own emotions and grief (UNAIDS Technical Update, 2000:15).

**Prison:** refers to an institution whereby all wrongdoers awaiting trial and those found guilty and sentenced are kept and locked up against their will for a specified period from a month up to life imprisonment as determined by a court of law (Hornby, 1974:664).

**Correctional Centre:** the definition is the same as “prison” and both concepts have been used interchangeably in this study. This was necessary because Correctional Services is currently in a stage of transforming “prisons” into “Correctional Centres”, which will be places of new beginnings for offenders, in line with the Department’s rehabilitation focus. Thus all newer policies and documents use this terminology.

**Prisoner:** refers to a person kept or incarcerated for crime committed, has been tried and found guilty by a court of law, and sentenced to a particular period of imprisonment (Sykes, 1982 :818).

**Offender:** is the same as the above definition and has been used interchangeably with the term “prisoner” for the same reasons mentioned under “Correctional Centre” above.

**Offender-patients :** refers to offenders/prisoners who are ill and confined to prison hospitals.

**Prison hospital :** means an inpatient health facility in prison which is equipped to care for, treat and house sick inmates as inpatients.

**Terminally ill:** refers to a medical diagnosis of a person who is ill, with little chance of recovery.

**AIDS:** is defined as a syndrome of opportunistic diseases, infections and certain cancers, which eventually kill a patient (Van Dyk, 1999:10).

## **1.15 STRUCTURE OF THE REPORT**

This report will consist of four chapters, which will cover the following topics:

Chapter 1: Introduction and Methodology

Chapter 2: Theoretical Overview Of Palliative Care And Related Issues

Chapter 3: Results and Discussion

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# **CHAPTER 2**

## **THEORETICAL OVERVIEW OF PALLIATIVE CARE AND RELATED ISSUES**

### **2.1 Introduction**

Palliative care is historically linked internationally to hospice work with cancer patients. Hospice programmes emphasize humane care designed to provide the best quality of life for terminally ill persons (Thigpen & Hunter, 1998: 1). With the advent of the HIV and AIDS pandemic, the principles underlying hospice care to cancer patients was extended to patients who were terminally ill with AIDS. Many challenges are faced by caregivers in rendering palliative care to AIDS patients in the terminal stages, because of the unpredictable nature of the disease and the stigma attached to it. Even more challenges are faced when offering palliative care to special populations such as offenders in correctional settings.

This chapter contains the theoretical overview of palliative care and related issues. The researcher considered it important to include the following broad themes:

- The global statistics of HIV infections and AIDS related deaths.
- The prevalence of HIV and AIDS in prisons.
- The continuum of HIV and AIDS treatment and care.
- Challenges to HIV treatment and care in correctional settings.
- Palliative care with a specific emphasis of its applicability to correctional settings.

In this study overseas as well as local literature was consulted.

## **2.2 Global Statistics of HIV and AIDS**

It is important to be aware of the global statistics of people who are infected with the virus or dying from the disease, as it provides an indication of the general extent of the problem and can be used to anticipate services and resources needed. It also guides the planning of services.

At the end of 2004 approximately forty million people were living with HIV/AIDS worldwide. Globally an estimated five million people were newly infected and three million people died of AIDS in 2004

(<http://www.avert.org/worldstats.htm:2004>). Sub-Saharan Africa, the most severely affected region of the world, accounted for over 3 million of these new infections and 2.3 million AIDS deaths. Every day in 2003 an estimated 14 000 people were newly infected globally with HIV. More than 95% of the HIV-infected people live in low and middle-income countries where access to antiretroviral therapy and proper nutrition may be problematic (World Health Organization, 2004:2).

South African statistics are of major concern. South Africa already had 4 million HIV and AIDS patients by December 2000 and 5.3 million by the end of 2003. It is anticipated that this figure could increase to 6.1 million infected people by 2005, and to 7.5 million people by 2010 (Body Positive, 2001:1). This means that by the end of 2005 15.25% of the South African population could be HIV-positive.

## **2.3 Prevalence Of HIV And AIDS In Prisons**

Since the prison community emulates society, one can anticipate the problem in prison will follow similar trends, or even reflect a worse case scenario, as research conducted by the Human Rights Watch/HIV/AIDS in Prison (2003:1) has shown that correctional institutions have six to ten times higher infection rates than the general population. Pagliaro and Pagliaro (1992: 201-214) agree that the prevalence of HIV infection and AIDS among inmates in correctional institutions is increasing worldwide at such an alarming rate that this population group is currently identified as one of the highest risk population groups for HIV infection and AIDS.

According to the Human Rights Watch Prison Project (2003: 2) in the United States in 1994 there were 5.2 cases of AIDS per 1000 prisoners, nearly six times the incidence found in the general population. According to the same source (Human Rights Watch Prison Project, 2003: 2) French prisoners are estimated to be HIV-positive at a rate roughly ten times than that of adults in the general community. Similarly, prisoners in Brazil and Argentina, have even higher levels of HIV infection compared to members of the community.

A study tabled during the International AIDS Conference in Durban in 2000 (Presentation to the Portfolio Committee on Correctional Services: HIV/AIDS Debate, 2002: 1) revealed that in Zambia the infection rate amongst prisoners was 27%. According to the same source a UNAIDS report in 1999, rated Zambia as having the fifth highest infection rate in Africa, while South Africa was rated sixth. It can therefore be assumed that the prevalence in South African prisons may not differ that much from that of Zambia.

A survey conducted at Medium B prison in Durban found an even higher percentage of HIV positive prisoners in the prison population. Goyer (2003:4) estimated that 41% of the prison population was HIV-positive during 2002. However, the Department of Correctional Services advised that care should be taken in extrapolating from this sample as it was not representative of all South African prisons (Presentation to the Portfolio Committee on Correctional Services: HIV/AIDS Debate, 2002: 1). However, these estimates are nonetheless alarming even if it is in one South African prison. These figures have major implications for the provision of care services for AIDS patients in prison since the global trend is an increase in numbers of people in the terminal phase and dying of AIDS.

## **2.4 Common Challenges to HIV And AIDS Treatment**

### **In Correctional Settings**

The provision of treatment and care for HIV/ AIDS offenders is more complex in a correctional setting. UNAIDS (2003:1) reports that patients with HIV and AIDS in the general population have rights to health, security of person, equality before the law and freedom from inhuman and degrading treatment. The World Health Organization's equivalence rule states unequivocally that whatever health care and prevention is available to the community at large should also be available to the incarcerated community (WHO/GPA/DIR/93.3:1).

The upholding of patients rights are more complicated when dealing with prisoners as other stakeholders who come into contact with prisoners also have rights. Therefore, the rights of prisoners, prison personnel, and those of communities from where prisoners come and to which they return, have got to be balanced and carefully considered in treatment and care models (Human Rights Watch Prison Project, 2003:3). Protecting those on the inside ultimately protects those on the outside, as offenders come from and return to communities.

In South Africa “ more than 25 000 prisoners were released from prison every month and the same number received from the courts” (Fagan, 2004:18), highlighting the large number of offenders that move in and out of prisons to communities on a monthly basis, making the problem difficult to handle.

According to Perez (1997: 3) and Haggerty (2000: 2-5), some of the challenges faced in providing care and treatment to HIV/AIDS patients in correctional settings are as follows:

- **Security Versus Care**

Prisons are mostly concerned with security, limiting prisoner movement and keeping tight control on when and where prisoners are in specified locations (Haggerty, 2000: 2). This focus on security impacts negatively on the provision of and access to care and treatment. Haggerty (2000: 2) further states that more resources, energy and time are spent on security rather than on treatment and care.



- Inadequate Access To Health Care

Perez (1997:3) is of the opinion that the most serious problem faced by HIV-infected prisoners is the lack of adequate medical care in prisons for the treatment of HIV and AIDS. Perez (1997:3) further states that patients with HIV infections do not receive appropriate medication or physical examinations, and lack access to proper laboratory monitoring of viral levels and T-cell counts. This lack of services fosters a system in which inmates suffer with severe complications, despite proven prophylaxis medication that might offer relief. Perez (1997:3) also states that there is often no chronic care system that exists within correctional systems. Health care, including HIV care, is managed incident to incident, with no continuity of care and no one provider who is managing the whole patient.

- Supportive Services and Counselling

As reflected in the treatment and care model (Avert.Org: 2004) supportive services are essential in the proper management of HIV and AIDS patients. Supportive services are also central to palliative care. In prisons there are very few support systems for inmates with HIV or AIDS. Prisoners lack support from family and friends from the outside as visiting times are restricted by prison policy. In addition offender-patients who are hospitalized are removed from other inmates in the prison. These inmates can be a tremendous source of support for the patient.

Staff may be also culturally insensitive or outwardly reluctant to effectively counsel people infected with HIV (Perez, 1997: 3).

In many facilities, the staff are either poorly trained, or not trained at all to understand the nature of the HIV pandemic and how to react or empathize with prisoners.

This, coupled with correctional staff having to deal with large numbers of patients with limited resources at their disposal, and the lack of active support from management may overwhelm them. The lack of support and counseling for patients who are ill with HIV and AIDS in a prison situation tends to disempower patients and increases their feelings of hopelessness and helplessness.

- **Stigmatization and Lack Of Confidentiality In Prisons**

AIDS is a disease that causes the sufferer to be stigmatized and marginalized by society (Perez, 1997: 3). The stigma of the disease is of particular significance in prison, because of the institutional nature of the environment. Many prisoners refuse to be tested and remain undiagnosed because there is little confidentiality in prison. There are many mechanisms in prison that may cause an offender's status from being revealed without him/her wanting to disclose his/her status, for example, non-medical people may get access to medical records that are confidential; staff may have a list of all inmates who are scheduled to see a visiting doctor; or they are exposed when having to wait in medical lines outside the prison hospital. The negative attitudes of staff towards prisoners may also prevent the former from maintaining confidentiality (Haggerty, 2000: 3).

- **Adherence To Medication**

Adherence to medication is vital to treatment and successful patient outcomes. In the general community there are two ways of dispensing medication, namely, keeping on person (KOP) and directly observed therapy (DOT). These methods are used to administer medication in prisons.

With KOP, inmates are issued a days or a week's worth of medication to keep in their cells and take at the appropriate times. However, prison rules and policies make the implementation of this system a challenge, as the prison schedule may not allow for appropriate meals or fluids being available at the appropriate time (Haggerty, 2000: 4).

Medication is often stolen for re-sale to other inmates. Also as discussed earlier the issue of lack of confidentiality in the prison compounds the problem. DOT means that the inmates must be released from their cells to stand in a pill line. Someone supervises the taking of the medicine and ensures that it is swallowed. Lock-up or strict security rules often make it impossible for inmates to go to the pill line. To make matters worse, medication delivery often breaks down when inmates are transferred from one institution to another or even one section to another within the same institution, or are taken to court (Haggerty, 2000: 4).

According to Haggerty (2000:4) a further challenge is that the HIV population is spread throughout the entire prison system and amongst all health care providers, making the dispensation and monitoring of adherence to medication even more difficult.

- **Inadequate Specialist Medical Care**

According to Haggerty (2000:2) there is generally a lack of HIV-specific medical expertise in prisons, as the poor working conditions and uncompetitive remuneration rates draw doctors to prison who have little or no first hand experience in treating HIV in their communities. Haggerty (2000:2) is of the opinion that this limited knowledge of HIV/AIDS is dangerous considering that studies have shown a direct correlation between practitioners' HIV experience and positive patient outcomes. Engle (1999:4) is also of the opinion that infectious disease specialists should be seeing patients initially, before deciding on a course of therapy. Making that initial determination of therapy has a major impact on whether therapy will be changed later on. This lack of specialist care is a problem in the prison. In addition AIDS patients often need to be seen by a variety of specialists for different types of opportunistic infections they develop in the course of the disease. This is difficult in the prison where co-ordination of specialist care is hard to achieve.

Engle (1999: 4) discusses an interesting managed care system developed by the Department of Correctional Services in New York which, if managed well, could be considered as an example in dealing with the problem of uncoordinated services. The managed care system is based on highly formalized procedures in working with outside service providers. The prison doctor arranges the consultation with an appropriate specialist. The specialist consultant examines the patient and makes recommendations, which are sent to the prison doctor for implementation. However even in this managed care system practical problems were experienced. There was no consistent system to ensure that the specialist's recommendations were followed.

There was little or no co-ordination between the specialist and the primary care physician. They never talk to each other, but just pass the patient's papers back and forth (Engle, 1999: 5). Thus the provision of adequate specialist care in prisons is a worldwide problem. This gap in the treatment and care continuum can have negative repercussions for the holistic treatment of the patient.

- **Lack of Education, Prevention and Awareness Programs**

Educational and awareness programs are important to patients who are terminally ill with AIDS. Programs can empower them with information about, for example, healthy living and treatment compliance. These programs are scarce in prisons where the focus is still largely on prevention of the spread of HIV. There is a need to ensure that there is a balance in the various programs because, as discussed earlier, more people are in the terminal phases and dying of AIDS. However, even where education and awareness programs are in place, implementation of the information learnt is difficult because of contextual constraints.

- Difficulties In Addressing Cultural and Traditional Practices in Prisons

According to Sandoval (2003: 301) it is important to have an understanding of the cultural context within which palliative care services will be provided. In 1998 the World Health Organization supported the use of traditional healers in treating patients with HIV/ AIDS. They cited many benefits to traditional healing.

Treatment tends to be more personal and, whilst it may be mixed up with religion and superstition, it is more supportive of the patient as a person rather than simply as a subject (Eden, 2001:1). This is confirmed by other literature.

Felhaber (cited in Van Dyk (1999: 119) that traditional African treatment is holistic in nature because it involves physical, spiritual, psycho-social and transpersonal aspects in its practices, that is, it not only takes physical signs and symptoms into consideration, but also the state of the patient's social and spiritual relationships, as well as certain internal psychic states such as anxiety and guilt.

People with HIV and AIDS may become frustrated with the management of their disease and may be willing to try anything in the hope of staying healthy for longer. Traditional treatment is thus in line with the principles of palliative care, which advocates holistic treatment and care.

Cultural and traditional practices are often not practiced in a prison situation because of the difficulty in dealing with large numbers of offenders with different belief systems.

In the researcher's opinion there is a further problem in South Africa in that the health professionals who visit prisons may not speak the language of the majority of the inmates and understand the culture of the prisoners. This could cause misunderstandings and frustrations in the provision of treatment and care for the patient.

- Inadequate Knowledge of the Prevalence of HIV and AIDS in Prison

Most correctional facilities worldwide do not accurately know the prevalence of the infection rate in their facilities (Engle, 1999: 1). This makes it difficult to plan for services. In South Africa it is difficult to estimate the prevalence rate as mandatory testing is considered unconstitutional and against the rights of the incarcerated individual. It is also against the World Health Organization's guidelines in dealing with HIV and AIDS in prisons (WHO/GPA/DIR/93.3). It is encouraging to note however that the Department of Correctional Services in South Africa is in the process of embarking on a prevalence and attitude study relating to HIV and AIDS, with the participants in the study remaining anonymous to overcome this limitation (Presentation to the Portfolio Committee on Correctional Services: HIV/AIDS Debate, 2002:1).

- Complications Caused by Prison Rape

It is conservatively estimated that one in ten prisoners will be raped at least once during incarceration (McMurray, 2002: 5). This complicates the management of offender-patients with AIDS.

According to U. S. Supreme Court Justice Harry A. Blackmun in *Farmer v. Brennan* "Shame, depression, and a shattering loss of self esteem accompany the perpetual terror the victim must thereafter endure" (Ludlow, 2000:4). The victim has to deal with both severe physical and psychological pain, which might impact on his responses to the care services being offered to him. The trauma associated with rape was confirmed by Rape Crisis who had conducted a training program with rape survivors at Pollsmoor Prison in the Western Cape between August and October 2001. They found that for many survivors the possibility of facing HIV and AIDS, in addition to the trauma of the violation of rape, is an overwhelming concern (Harvey, 2002:4).

Services available at the asymptomatic stage of the treatment and care model will also be important for people who have contracted AIDS through rape. Since there is a possibility of prisoners becoming infected with HIV because of rape in prison, care and support has to form part of the treatment process to cope with this double trauma. As already discussed this is inadequate in prisons. For rape survivors in prison, the typical support networks of family and friends are not available; access to health facilities is limited and there appears to be no structure to deal with the immediate trauma (Harvey, 2002:4).

From the above one can see that there are many challenges in prison to providing treatment and care to offender-patients generally and specifically to those who are infected with HIV/AIDS.

## 2.5 HIV/AIDS Treatment And Care

A treatment and care model as reflected in Avert.Org

([http://www.avert.org/treatmentand\\_care.htm](http://www.avert.org/treatmentand_care.htm): 2004) is presented below. This

model is important to this study because it highlights the progression of different

stages of the disease that a patient who is diagnosed with HIV and/or AIDS

follows. It presents a continuum of care that starts at the diagnosis of the disease

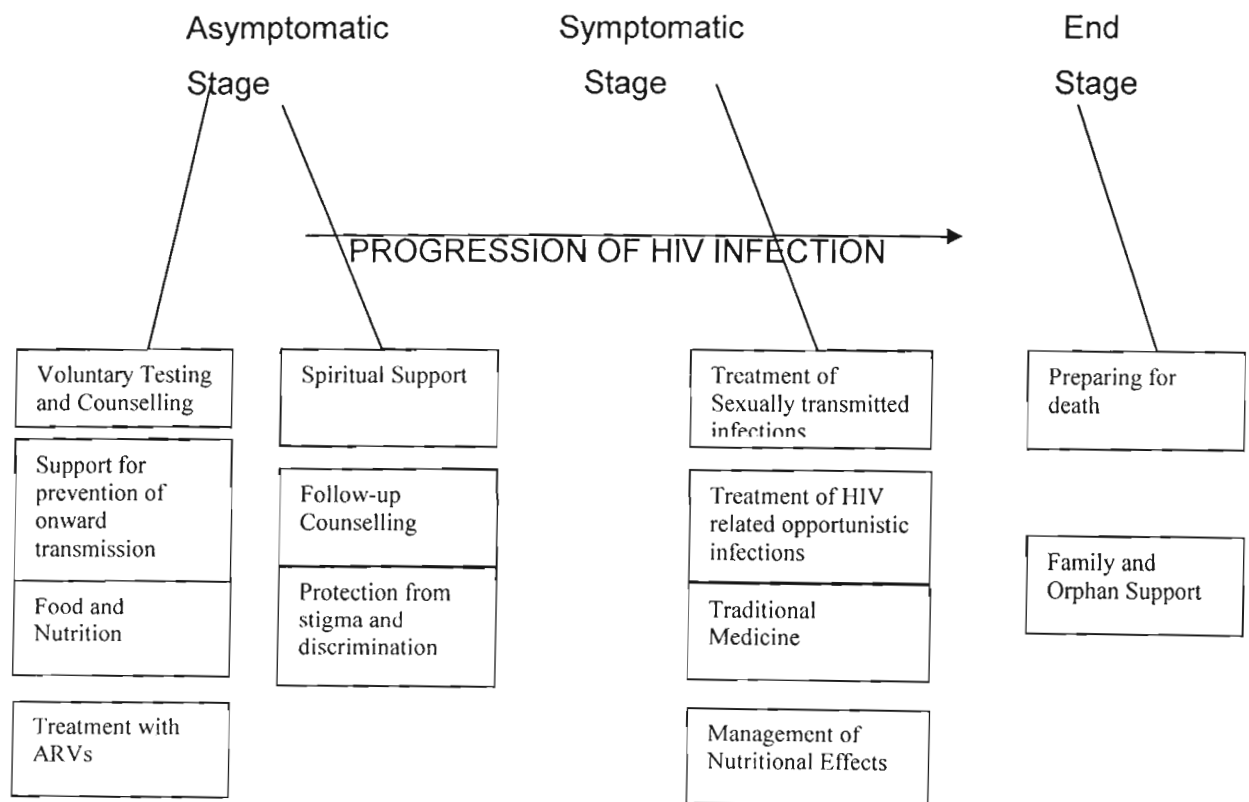
and continues through to the period of bereavement. Patients may move back

and forth between the various stages depending on their response to the

treatment.

### A Treatment & Care Model

Diagram 1: Treatment & Care Model



Source: Avert.Org:2004



In terms of the above model HIV-positive people have differing needs according to the stage of their infection. Caregivers need to be aware of these needs in order to respond appropriately. The first stage in the continuum is when people are asymptomatic, that is, when they have no signs or symptoms of their infection. At this stage they need support to prevent the onward transmission of the disease, they need to ensure that they are eating well, they may need to start on antiretroviral treatment and they need spiritual support, counselling and protection from stigma and discrimination, as this adds to the trauma of dealing with the diagnosis (Avert.Org: 2004).

The second stage is when people have symptoms of HIV infection and need to be treated for the various opportunistic infections. In this stage it is important for caregivers to be culturally sensitive when providing care and treatment as some patients may want to engage traditional healers to supplement the treatment being received (Avert.Org: 2004).

The third stage relates specifically to the support and care of people who are terminally ill and nearing the end of their lives. People who are nearing death are frequently afraid of dying in great pain. Patients need to be assured that pain relief will be carried out to the point of death. Caregivers from Msunduzi Hospice agree that pain control becomes significant at stage three of this model. As such pain control is one part of a comprehensive approach to care for a patient and his family (Msunduzi Hospice Workshop: 2004). This service forms part of the continuum of holistic care that is inherent in the palliative care paradigm (Avert.Org: 2004).

Preparation for death forms an essential part of the end stage of the model. Some patients may want to talk about their fears of dying, or may want to finalize plans for their families. Family and child support is also considered important at this stage. The above-mentioned treatment and care model is generic and could be applicable within a correctional environment.

## **2.6 Palliative Care**

Palliative care is a model of care that is increasingly being used in communities and in correctional settings world wide to deal with AIDS patients. Palliative care aims to achieve the best quality of life for patients (and their families), suffering from life threatening and incurable illness, including HIV and AIDS. Crucial elements are the relief of all pain, that is physical, psychological, spiritual and social, and enabling and supporting caregivers to work through their own emotions and grief. It is a misconception that palliative care deals only with patients who are approaching death. Central to this philosophy is the belief that everyone has the right to be treated, and to die, with dignity, and that the relief of pain is a human right and essential to this process (UNAIDS Technical Update, 2000: 2). The following definitions will expand the concept further.

### **2.6.1 Definition of Palliative Care**

The World Health Organization defines palliative care as:

“ The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families” (Doyle, Hanks et al, 2003: 3).

By way of expanding and explaining the definition, the World Health Organisation extends it as such: “ Palliative care.....affirms life and regards death as a normal process.....neither hastens nor postpones death.....provides relief from pain and other distressing symptoms....integrates the psychological and spiritual aspects of care.....offers a support system to help the family cope during the patients illness and in their own bereavement” (Doyle, Hanks et al, 2003: 3).

The HIV/AIDS Bureau of the Health Resources and Services Administration in the United States Department of Health and Human Services (O'Neill & Barini-Garcia, 2003:1) has adopted the following working definition:

“ Palliative Care is patient and family-centred care. It optimizes quality of life by active anticipation, prevention, and the treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs. It facilitates patient autonomy, access to information, and choice.”

Doyle, Hanks et al (2003: 3) add that palliative care remains sensitive to personal, cultural and religious values, beliefs and practices. It may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

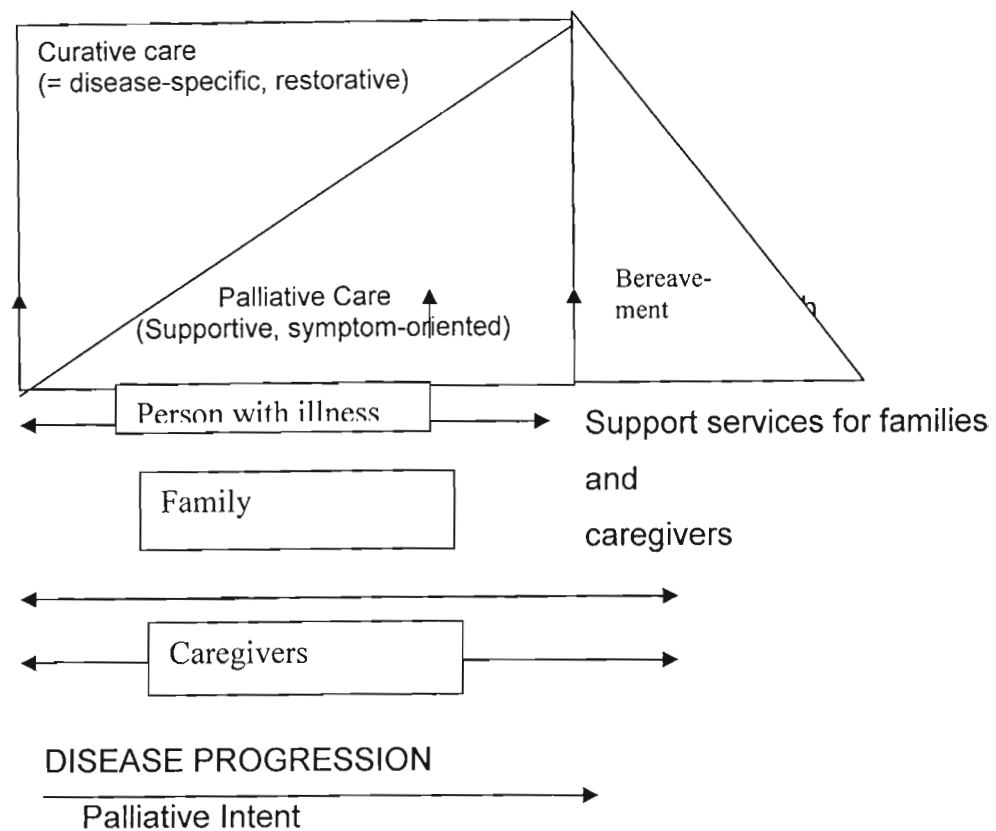
Thus in reviewing the above definitions palliative care looks at the total needs of the patient, is family centred, is culturally sensitive, and takes into account the need for care for the caregivers. It is holistic in its approach and occurs on a continuum.

### **2.6.2 Philosophy Of Palliative Care**

Palliative Care emphasizes the maintenance of human dignity, quality of life, comfort and concern for the individual, his/her family and significant others. The philosophy of palliative care also states that it may start at a time of diagnosis and becomes more intensive as treatment changes to symptom management, support, and preparation for death as depicted in the treatment and care model discussed earlier.

This continuum of care can also be graphically depicted as reflected below:

**Diagram 2: Integrated Model Including Both Curative and Palliative Care**



(Source: World Health Organisation: 1990)

This model is based on a continuum of care, depicting the type of care with the progression of the disease. This aspect makes it compatible with the treatment and care model discussed earlier (Avert.Org: 2004). The palliative care intent becomes more significant with the progression of the illness proceeding into death.

It is important to understand the philosophy of palliative care as it guides practice.

The suggested philosophy of palliative care by the Canadian Palliative Care Association (1995:16) states that:

- Every individual has the right to make an informed decision about health care options that will help to optimize the quality of his life during a life-threatening illness, and especially when dying;
- Palliative care strives to meet the physical, psychological, social, and spiritual needs of individuals and families with due regard to their personal, cultural and religious values, beliefs and practices;
- Care should be delivered in a client focused, family-centred environment;
- The individual has a right to access palliative care from an interdisciplinary team of appropriately trained professionals and volunteers, who receive continuing palliative care education and evaluation;
- The individual has a right to quality of life by means of effective pain control and managing of symptoms effectively as a patient will not respond to counseling if he is in pain and/or is nauseous.

Therefore from the above discussion one can assume that in prisons where there is denial of civil liberties and security plays a major role, the philosophy of palliative care would be difficult to put into practice.

### **2.6.3 Principles Of Palliative Care**

The following principles of palliative care have been derived from the philosophy. It is important to this study as it guides practice. The principles have been adapted from the Canadian Palliative Care Association, 1996: 16-17 and Saskatchewan Health, 4-5 (Frohlich, 2003:19).

- **Comprehensive Care**

Palliative care is comprehensive in that it is directed towards meeting the physical, psychological, social, and spiritual needs of individuals and families with due regard to their personal, cultural and religious values, beliefs and practices.

- A Trajectory of Care  
Palliative care has three phases:
  - Initial/Acute Phase: refers to care at the time of diagnosis or when the prognosis changes. The focus at this stage is on aggressive interventions.
  - Chronic Phase: refers to “being ill” and involves the management of symptoms.
  - Final Phase: is defined by the person’s creative management of his/her mortality with an emphasis on physical care and symptom management.
 The above phases can be equated to the three stages of the treatment and care model discussed earlier.

- Access To Care  
Patients should have access to care twenty- four hours per day, seven days per week. In order for patients to access the care services, these services should be provided in an understandable language.
- A Client-Centred Approach  
The individual and family control the decisions that determine the patient’s care. Information should be available to the patient and family members to enable them to make informed decisions.
- Right To Information  
The individual has the right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options. This information enables him to make decisions about his care and treatment.
- Right To Choice/Empowerment  
The individual has the right to be heard, the right to be informed, and the right to share in decisions in collaboration with the service provider and caregivers. The choice of the individual about the care and the care setting needs to be respected.

- **Interdisciplinary Team**  
Care to the patient is provided by an interdisciplinary team of caregivers, who have a diversity of training among them, and who share the goal of improving the quality of life of the individual.
- **Continuity Of care**  
A coordinated, continuous plan of care is maintained across all settings from the time of admission of the patient to bereavement support of the family.
- **Quality of care**  
Care is delivered within the accepted standards of care, conduct and clinical practice for palliative care. These standards include issues like providing the patient and family with choices about care, pain and symptom management; psychological, social and spiritual support; grief and bereavement support; emergency services; and continuum of care with an effective referral system in place.
- **Education, Information, Research and Advocacy for Palliative Care**  
Education, information, research and advocacy for the development of palliative care standards and resources are essential to improve the delivery of care services.
- **Evaluation**  
Palliative care services should be evaluated regularly to maintain the standards of conduct and practice (Frohlich, 2003:19).

Fox in O'Neill and Selwyn et al (2003:18) also lists core elements that he believes are important to palliative care. The researcher will elaborate on those not discussed by The Canadian Palliative Care Association, 1996; 16-17 and Saskatchewan Health; 4-5 as mentioned above:

- Palliative care depends on effective communication and relationship building between the patient, family and caregivers, within a model of diverse expertise and interdisciplinary teamwork. It cannot be practiced within a framework of authoritative hierarchy where the patient and family are dictated to by caregivers.
- The goals of care include relief of suffering, control of symptoms, and restoration of functional capacity, to ensure that the dignity of the patient is not impaired.
- Caregivers in palliative care consider the patients' subjective experiences, for example, his/her experience of pain, to be as important as objective clinical data gathered during the treatment process.
- Diagnosis is not a pre-determined goal and is only pursued if it conforms to patient-determined goals of care.
- The treatment and care plan is tailored specifically to each patient, according to the patient's values and preferences, and not decided unilaterally by the physician.

#### **2.6.4 Goals Of Palliative Care**

According to O'Neill and Selwyn et al (2003:17) palliative care seeks to provide the best quality of life for patients and families using a model in which the goals of care are collaboratively developed with care providers according to the wishes of the patients and families. This model emphasizes communication, collaboration, and the willingness to accept patient-focused outcomes as paramount and to respect patients' wishes regarding such important issues as quality of life or cessation of therapy.

#### **Advance Care Planning**

The focus on the goals of care incorporates the concept of *advance care planning*, which is an important component of palliative care.

Advance care planning includes planning of both medical and psychosocial elements.



**The medical elements may include:**

- Decision making about the risks and benefits of specific therapies, for example antiretroviral therapy.
- The importance of quality-of-life elements in these decisions, for example, the choice of a potentially toxic, time consuming intervention that might prolong life versus more palliative measures that would improve short term quality of life, but not extend it.
- Decision about particular medical interventions, for example, cardiopulmonary resuscitation or artificial nutrition or hydration.

**Psychological elements may include:**

- Family ambivalence or conflict about care plan decisions
- Guilt or other emotional “unfinished business” that may affect decisions regarding care planning
- Concerns that any limitation on curative treatment interventions may represent abandonment of the patient or lack of commitment or concern on the part of the care provider.

Anticipatory advance care planning is a way to enable patients and families to make decisions that are true to their basic beliefs, values and concerns. The most effective way to achieve this kind of decision making is in the context of an interdisciplinary team which can help the patient and family process and act on information on many levels at once (O'Neill, Selwyn et al, 2003:24 - 25).

## 2.7 Ethical Issues In Palliative Care

Palliative medicine is informed by ethics that guide clinical decisions. According to Jansen and Johnston et al (2003: 349) two important ethical issues are relevant, namely the ethics of honoring patient dignity and the ethics of promoting patient well-being:

- The Ethics of Honoring Patient Dignity

Patients in need of palliative care also have desires about the kind of treatment they would like to receive. The physician has an ethical responsibility not to impose unwanted treatment on the patient, for example, if a competent patient refuses life-sustaining therapy, physicians must not administer it, even if they believe that it is necessary to keep the patient alive (Jansen and Johnston et al, 2003:349).

Patients must be informed about treatment options open to them. Patients must also be assisted to think about the medical treatment they would like to receive should they become incapacitated. To achieve this, patients may complete an advance directive or appoint a surrogate decision maker. With respect to patients with HIV and AIDS, obtaining an advance directive can present special challenges. Fear of social and family stigmatization can make these patients reluctant to engage in end-of-life planning with their physicians, for example, some patients may attempt to keep their diagnosis a secret from their family members (Jansen and Johnston et al, 2003: 350). However at times honoring a patient's dignity may, require the physician *not* to comply with the patient's request, for example, when the patient asks for a medical intervention that is clearly medically inappropriate, or the patient asks the physician to shorten his life during the final stage of his illness, or asks for care that is bio-medically futile (Jansen and Johnston et al, 2003:350).

- Promoting the Well-being Of a Patient

A patient's well-being is promoted by advancing his/her interests. A primary objective of palliative medicine is to provide relief for pain and suffering. Although these experiences are personal and subjective, good palliative care attempts to identify and measure them, by asking patients to rank their pain on a scale of 0 to 10. Doing so provides guidance to clinicians who seek to restore them to a level of comfort (Jansen and Johnston et al, 2003:350).

The ethical issues discussed above are extremely important as it underpins the principles of palliative care to patients with HIV and AIDS. Caregivers, especially physicians, need to be consciously aware of these ethical issues as it will guide their practice with patients who are terminally ill.

## 2.8 HIV And Palliative Care

In South Africa the policies of the Department of Health promotes the provision of palliative care services in communities. O'Neill and Selwyn et al (2003:1) agree that the principles of palliative care can effectively be integrated into the delivery of care and services to people living with HIV/AIDS, throughout the continuum of illness. Neil and Selwyn et al (2003: 1) further state that palliative care is *complementary* care, not *alternate* care, which means that providers should focus their attention on comfort, relief of suffering, and quality of life throughout the course of the HIV disease.

It should not be provided only when disease-directed therapy fails or is unavailable. It is a mistake to adopt a palliative perspective and approach only at the last stages of illness. This thinking is in line with the treatment and care model discussed earlier. Caregivers should thus focus their attention on comfort, relief of suffering and quality of life throughout the course of the HIV disease.

In the early years of the AIDS pandemic, clinicians were compelled to learn about palliative care, as there was no cure for the disease. With the advent of antiretroviral therapy and the ability to control HIV disease, it remains important to incorporate relevant aspects of palliative care in the comprehensive management of patients with AIDS. Rather than being “*either-or*”, curative and palliative approaches to HIV care need to be “*both-and*”, and one paradigm need never fully substitute for the other (O’Neill, Selwyn et al, 2003:5).

### **2.8.1 Palliative Care and The Challenge Posed By HIV and AIDS**

Although palliative care has been extended to people with HIV/AIDS there are specific challenges because of its specific dimensions. According to UNAIDS (2000:3-4) some of these challenges are:

- The Complex Disease Process

In providing treatment and care services to patients with HIV and AIDS, it is important for caregivers to understand that this disease is far more complex than the palliative care services that has historically been provided to cancer patients. The course of HIV and AIDS is highly variable and unpredictable, with a wide range of potential complications, rates of progression, and survival. Some patients remain free of symptoms for a long time; others experience alternating periods of increasing dependency with episodes of acute illness, or suffer frequent non-life threatening complications throughout their infection. Patients also vary in their emotional responses to the infection; this again complicates the planning and delivery of palliative care.

The roller-coaster nature of HIV and AIDS thus poses a real challenge to the provision of palliative care services to patients who are ill with the disease. The unpredictability of the disease puts a strain on the patient and caregivers.

- Complex Treatment

A wide range of treatment for HIV/AIDS patients is now available.

Palliative care in HIV must be able to adapt to the fluctuating yet ultimately downward course of HIV disease. Whilst adherence to medication stabilizes the course of the disease, other factors can be equally important in optimizing clinical outcomes.

According to O'Neill and Selwyn et al (2003:2) these factors include a wide range of hard- to- control socio-economic as well as personal characteristics: an understanding of the disease process; empowerment in relation to personal health; a safe place to live; freedom from pain and distressing symptoms; adequate nutrition; treatment for substance abuse; depression and other mental illness; hope; adequate help of friends, family and other caregivers, especially when functional status is diminished and disease progression is ongoing, These challenges can be met successfully by using a palliative care framework to approach the patient, caregivers, family, loved ones, and the health care system.

- Stigmatization and Discrimination

People living with HIV and AIDS face a very specific set of psychosocial problems. People are reluctant to be open about their HIV status because of the fear of stigmatization and discrimination, thus increasing their feeling of isolation. Caregivers may also be wary of revealing the positive status of a sick relative. A lot of the time people with HIV are from marginalized or minority groups, such as drug users, prisoners, homosexuals, or sex workers. They may have less established support networks, and thus face added discrimination.

The fear of stigmatization and discrimination provides a real challenge to providing palliative care to prisoners who are terminally ill with HIV and AIDS in prison.

- Complex Family Issues

HIV and AIDS has a major effect on families, especially in areas of high prevalence and where most patients are young and economically active. Both partners in a relationship may be infected. If one partner is infected, the other will worry and may even be angry. If a child is infected, usually both parents are infected as well. Siblings may also be infected. Financial problems are experienced when the breadwinner becomes ill. With regard to offenders who are ill with HIV and AIDS, the burden on the family is increased. Family members have to visit these patients in prison, which is a further drain on their financial resources. They have to provide emotional support to the patient as well, and may also experience some of the frustrations of the bureaucratic prison environment that provides a challenge to an effective treatment and care programme.

- The Burden On Health Care Workers

Caregivers who provide treatment and care services to patients with HIV and AIDS face conditions unique to the disease. In this study this situation was aggravated by the fact that the HIV and AIDS patients are in prison, which is an institutionalized setting with a specific culture. So many patients are young and health care workers caring for people with late stage HIV disease face the death of all of their patients.

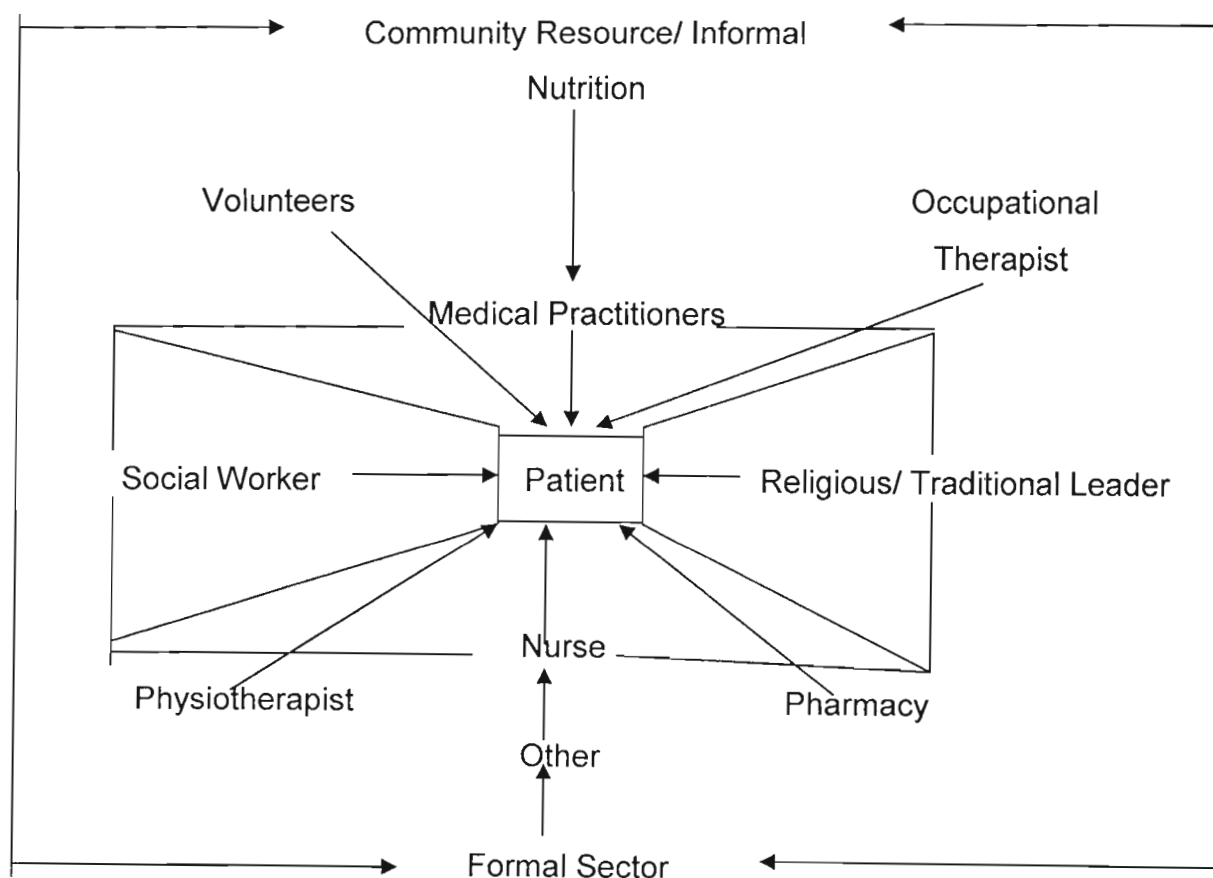
In a prison setting health care workers are compelled to attend to large numbers of patients with varying ailments, in addition to those with HIV and AIDS. Eventually, workers may become withdrawn and fatigued by multiple losses and the complex care needs of their patients. In palliative care, the mental health of health workers is vital if they are to remain empathic and effective in the direction and delivery of care (UNAIDS, 2000:3-4).

## 2.9 Integrated Team In Palliative Care

The integrated team approach in palliative care is most fully realized when it encompasses all the contributions of an interdisciplinary team. Patients and families experience the totality of illness, with medical, psychological, social, and spiritual dimensions. The interdisciplinary team can best implement a bio-psychosocial approach to care, regardless of which needs are expressed at any given time. The complexity of AIDS in all these dimensions requires this type of comprehensive, collaborative, and multi-levelled response (Kutzen, 2003:447).

The following is an indication of the various role players that may form part of the integrated team:

**Diagram 3: The Integrated Team in Integrated Palliative Care**



Source: Frohlich, 2003: 24

## **2.9.1 Specific Roles Of the Integrated Team Members**

- **Role of the Medical Practitioners**

Medical practitioners are involved with diagnosis, prognosis, symptom prevention, design of treatment plan, education and communication with staff, patient, and family regarding status and response to treatment.

Consulting physicians are responsible to primary medical providers and should work as part of the team. Specialists may include psychiatrists, ophthalmologists, neurologists, dermatologists, oncologists, gynecologists, orthopedists, or providers of any other specialist service (Kutzen, 2003:448).

- **Role of The Palliative Nurse**

The primary role of the nurse is to assist the patient in coping with the effects of advancing HIV disease. This includes attention to some of the most personal and intimate aspects of physical care, pain and symptom assessment and management, personal care such as bathing, control of odor, care of pressure areas, mouth care, bowel and bladder care, as well as patient and family education on anticipated care needs.

Research findings in New South Wales, Australia, (Taylor, Glass et al, 1997: 253), revealed that palliative nursing is also about:

- Dealing with death, which is an inescapable part of palliative nursing.
- Making connections with patients and their families, thereby ensuring that a special bond exists between the nurses themselves and their patients.
- Making realistic contracts with dying people and attempting to fulfill them, for example, making a contractual arrangement with a patient in not letting him suffer.
- Acting as an advocate by communicating with other people on the patient's behalf.



- Building interpersonal relationships by taking time to build the relationship, by developing trust and rapport, and through bonding and getting close.
- Facilitating support through the engagement of the family in the care and support of their loved one.
- Being involved in issues, such as what was going to happen to the dying patient, dealing with feeling personally responsible for covering all the work that needed to be done.

- **Role of Pharmacists**

Pharmacists assist medical practitioners with adjusting the doses of medication to reduce side effects, provide new information to the team, and educate patients and families about medication plans. They can thus form an integral part of the multi-disciplinary team (Kutzen, 2003:451).

- **Role of Physiotherapists**

The role of the physiotherapist is to provide physical assessment, education for patients and caregivers, and assistance in helping patients to stabilize gait and be mobile. As patients are living longer with HIV, more patients are living with neuromuscular deficits for longer periods of time. The role of the physiotherapist is more to maximize the patient's physical agility as a result of diminishing physical health rather than to improve function (Kutzen, 2003:451).

- **Role of Religious Workers**

Illness is a major life event that can cause people to question themselves, their purpose and meaning in life. Palliative care has long recognized that, in addition to physical and psychological symptoms, patients with advanced illness will suffer existential distress as well.

Existential distress deals with questions regarding the meaning of life, the fear of death, and the realization that they will be separated from their loved ones.

These issues take on greater importance in HIV/AIDS because of the stigma and judgment that still accompany people living with this disease. Spirituality plays a critical role in helping people to cope with their suffering, because the relationship with a transcendent being can give meaning and purpose to people's lives, to their joys and to their sufferings (Puchalski, 2003: 290).

The concept of spirituality is often poorly understood within health care. It is still viewed as being closely linked with religion and should therefore be addressed by chaplains. Palliative nursing care in the 21<sup>st</sup> century means embracing body, mind and spirit and is not limited to religious practices only. Health professionals therefore need to become more involved with the existential issues of living with a chronic illness. Research in the United States in 1997 (Wilkinson, 2000:4) revealed that 40% of respondents expected their doctor to discuss spiritual issues with them if they were seriously ill. Nurses spend more time with the terminally ill patients than most. They should, therefore, be involved in speaking the language of spirituality as part of their communication during episodes of care.

- **Role of Psychologist**

Psychological care is concerned with the psychological well being of the patient and their family and the provision of general emotional care and support. It is concerned with enabling the individual to express thoughts, feelings and concerns relating to illness, assessing individual needs and resources for coping, and ensuring that appropriate psychological support is available. A range of planned and informal interventions may be used, for example, communication skills to elicit concerns and to provide supportive care, counseling to facilitate reflection upon the illness experience, and specific psychological interventions to relieve anxiety or depression. Psychological care and support should be available at all times (Payne & Haines, 2002: 242).

- **Role of the Social Worker**

The goal of social work in palliative care is to help the patient and family deal with the personal and social problems of illness, disability and impending death, and to provide survivor skill-building and support. Social Workers assess many important areas of need for both patient and family, and help the family develop realistic plans for the present and the future. The strengths and challenges of each family unit are assessed and referrals made to available resources (Kutzen, 2003:449).

Social workers also assess cultural and socio-cultural factors unique to the patient and family, such as traditional medicine or alternate healing practices in the home.

Social workers assist when there is dysfunction within the family, for example, drug and alcohol abuse are common within HIV care.

One of the most important roles of social workers is advocacy on behalf of the patient and family (Kutzen, 2003:449).

- **Role of Nutritionist**

Nutritionists work with patients in all stages of the HIV disease, but are most needed in the terminal stages as both weight loss and malnutrition increase as the HIV disease progresses. Nutritionists can provide nutritional counseling and advise on nutritional supplements and appetite stimulants when this is needed. Nutritionists can be valuable team members in discussions of the pros and cons of end-of-life nutrition and hydration (Kutzen, 2003:450).

Each team member has particular expertise in his/her own field. However, all members share the responsibility for advocacy, enabling, support, truthfulness and mediation to prevent crises, minimize suffering and ensure that the patient and family remain the focus of care (Kutzen, 2003:447).

## 2.10 A Case For The Need For Training

Palliative care in corrections is a relatively new concept. Members of the integrated team are trained in their own areas of expertise, for example social work, and psychology, but not necessarily in palliative care.

The results of a study conducted by a nurse working for Msunduzi Hospice in Pietermaritzburg, during December 2002 (Berry, 2002:3) highlighted this need for training. Her study was prompted by comments her former colleagues made when she left to work at hospice – comments like “ morbid work, working with the dying” and “it takes a special person to work with hopeless cases.”

She also observed the inability of nurses to work with patients who required palliative care in hospitals. She sent out questionnaires to three local hospitals as part of the study. Her findings were as follows:

- 86% of nurses interviewed did not know much about palliative nursing care.
- 80% of nurses were uncertain about physical pain relief.
- On the topic of psychological pain, 52% stated that they are either too busy or too uncomfortable to discuss a patient's illness or prognosis with him.
- With regard to psychosocial pain, 43% showed no evidence of coping skills when dealing with a dying patient and his family, and admitted they felt hopeless.
- 90.5% of the nurses stated that they will benefit from training in palliative nursing care.

Although the study was a mini investigation, the results are profound and may be applied to a setting like corrections, where nurses also care for dying patients in a hospital situation. Although this study focused on nurses in provincial hospitals, the need for training can also apply to other professionals who make up the integrated team in palliative care.

## **2.11 Care For The Caregivers**

Palliative care includes care of the caregivers. The changing demographics of the HIV epidemic, along with the growing complexity of medical care, have created major challenges for the health professionals who provide curative and palliative care, and the informal caregivers who provide emotional and practical support to relatives and friends living with the disease (O'Neill and Selwyn et al, 2003:409).

Many of the burdens experienced by formal and informal caregivers are the same. Formal caregivers may experience concerns about contagion and not being able to "cure" the disease. The unpredictable course of the HIV disease can create significant burden, while attempting to control chronic symptoms and conditions clinicians must also be prepared to treat episodes of acute illness and therapy related side-effects (O'Neill and McKinney, 2003:412).

Additional sources of burden include repeated exposure to the death of young patients, ethical dilemmas, and finding the time to counsel and support informal caregivers. In a correctional setting informal caregivers may extend to offenders who work as volunteer caregivers. Formal caregivers may also be burdened by work-related stressors, such as work overload, unrealistic expectations of what can be accomplished, lack of decision making autonomy, communication problems and role conflicts, and inadequate medical resources and referral arrangements (O'Neill and McKinney, 2003:413).

Caregivers within a correctional setting are also exposed to the above challenges.

## **Strategies for Counteracting Burnout and Promoting Self-Care**

This forms an essential component in the palliative care model. There are a wide variety of strategies for preventing and managing burnout. Most of these strategies focus on ways of managing the care- giving situation rather than on eliminating or reducing stressors in the care- giving environment. Caregivers should therefore re-evaluate care giving demands and resources, clarify values and priorities, and adopt coping strategies that match the nature of the stressors (O'Neill and McKinney, 2003:418).

Six approaches to counteracting burnout and promoting self-care receive frequent mention in literature (O'Neill and McKinney, 2003:418):

- Use problem-focused strategies to cope with stress as opposed to emotion-focused strategies. Problem-focused strategies include gathering information, planning and taking direct action, as opposed to emotion-focused strategies, which include efforts to escape or avoid problems, emotional outbursts and self-accusation.
- Change care giving patterns by breaking down tasks into small acts of care, learning how to adjust the pace of care giving, asking others to help, and encouraging the care recipient to help with tasks and continue self-care as long as possible.
- Adopt relaxation tasks to manage stress and prevent burn-out. These techniques should fit with the individual caregivers interests, time and resources.
- Strive for good health by eating three balanced meals a day, exercising regularly, and sleeping between seven to nine hours each night.
- Maintain a life outside the care- giving role by getting away for a few hours, maintaining contact with friends, interests, hobbies and activities that once brought pleasure.

- Build a support network that provides emotional comfort and practical support, which reduces social isolation, and offers humor, recognition and encouragement.

In addition to the above, situational strategies attempt to reduce the incidence of burn-out by eliminating or modifying worksite stressors with regards to caring for HIV/AIDS offender-patients.

These strategies promote engagement with workers by:

- Establishing clear job descriptions and good referral mechanisms
- Setting realistic work targets
- Restructuring jobs to make work loads more manageable
- Providing training on HIV management, new approaches to pain and symptom management, and effective ways of communicating with patients and families
- Offering on site health promotional programs
- Encouraging staff to participate in policy decisions that affect their work
- Providing regular time off and appropriate rewards
- Scheduling regular memorial services for staff wishing to remember and grieve lost patients

(O'Neill and McKinney, 2003:422)

## **2.12 Palliative Care To Special Populations: Offender Patients**

Providing palliative care to special populations, for example, care to offender-patients, has an additional level of complexity. Many people who are marginalized from society and already underserved by the health care system have become distrustful of “the system” or have difficulty understanding the HIV disease process, much less the highly technical aspects of highly active antiretroviral therapy. People who belong to the marginalized groups may perceive palliative care as second-class care, which they are being offered instead of aggressive acute medical care. Since palliative care should be the result of an individual’s choice, the importance of gaining the trust of individuals in special populations becomes even more apparent when this dimension is added (Alexander & Schietinger, 2003:315).

This entails spending time with the patient, a luxury that caregivers in prisons cannot afford because of the many patients that require their attention.

### **2.13 Community-Prison Partnership In Palliative Care**

It is important to form partnerships with non-governmental and community based organizations who have specific skills and experience in palliative care. In South Africa the White Paper on Corrections (2005) stresses partnerships with community organizations as it views corrections as a societal responsibility. The White Paper has thus paved the way for partnerships with community and community based organizations in the delivery of services to offenders, including offender-patients.

One model of this community-prison partnership in America is the prison based hospice programme. Hospice programmes address the special needs of the terminally ill. In the United States this movement has slowly gained a foothold among state, federal, and municipal prison administrations.

According to a study conducted (Thigpen & Hunter, 1998: 3) twelve correctional departments in the United States have instituted a formal prison hospice programme at one or more sites, resulting in the existence of twenty eight formal hospice programmes. At least nine correctional agencies were providing some form of palliative care outside a formal hospice setting.

Thigpen and Hunter (1998:4) further described the different forms of hospice programmes in operation in these twenty eight United States prisons. Within correctional facilities some patients requiring hospice care are accommodated in separate units in the medical facility, or in non-separate housing in the hospital section, or in a separate 20 bed facility, or in private medical units in regional medical centers. Inmates requiring hospice care are housed in both single-cell and multiple-bed units, as determined by a variety of settings.



The hospice and palliative care programme in New York Department of Correctional Services utilizes community volunteers to provide companionship and support to hospice patients whilst the North Carolina Department of Correctional Services allows family members to assist patients with activities of daily living, under the supervision of a nurse and also allows inmates from inside the prison to visit patients (<http://www.graceprojects.org>).

The above indicates that there are models internationally that have succeeded in providing palliative care within a correctional setting. These positive experiences may be adopted and adapted to local situations in South Africa.

## **2.14 A Case Against Palliative Care In Prison**

Despite the development of hospice programs in prisons in the United States, as mentioned above, there is still some controversy in literature as to whether palliative care can be successful in a correctional setting.

Crowther, Rochford, and Richman (2002:3), looked at the issues of palliative care for the elderly in British prisons and cited a number of reasons why prisons are inappropriate for palliative care, namely:

- In a prison situation security and control take precedence over other activities because of the need to protect offenders, staff and members of the community. There are few resources and limited management support for treatment and care activities.
- Prisons are usually overcrowded and resources and activities are geared toward the majority of offenders who are not ill. Limited resources are available for offenders who are sick.
- Prison rules are generally coercive, top down from a mechanistic organization structure with rigid job specifications, for example, at night all patients in the medical center are locked within their rooms. The doors are opened only in a case of an emergency.
- There are no facilities for relatives and friends to stay overnight with the dying prisoner. They bring their own food into prison when visiting, which is subject to the conventional security inspection.

- It would not be cost effective or practical for each prison to have its own palliative staff. It may be possible for some prisons to be designated regionally as palliative centers. However, it is not known how many eligible prisoners would want to move from their own prison to the palliative center. This will also have implications for families to visit because of the greater distance to be traveled.
- Regard has to be taken of the effects of a dying prisoner on other prisoners and staff. Although it is not known how many nurses would like to be involved with palliative care in correctional facilities, in this study there was a strong feeling amongst nurses that prison is not an appropriate place to die in.

The above arguments against the provision of palliative care in prisons for patients who are terminally ill are extremely relevant. However, the reality is that there will always be prisoners in correctional facilities that are terminally ill and cannot be released to family or hospices in the community. The people who manage prisons are thus compelled to apply their minds as to how best to manage this situation, and are challenged to put strategies in place to cater for the holistic needs of terminally ill and dying patients.

## **2.15 Compassionate Release**

Compassionate release, also known as medical release in South Africa, provides a means for early release of inmates with terminal illness. According to MacDougall (1998: 9) it is a process that is used in the continuum of care by correctional facilities internationally. It is also a human rights issue as it concerns the right of the patient to die with dignity. MacDougall (1998: 9) further states that policies regarding compassionate release have been established in 59% of state prison systems in the United States. Greenspan in MacDougall (1998: 9) of the HIV/AIDS in Prison Project in California argues that the early release of inmates who are terminally ill is appropriate from both a fiscal and humane standpoint. She warns that should this not happen correctional facilities will be faced with healthcare costs spiralling out of control. She further states that compassionate release of inmates is more a political than a medical issue.

Legislation in California streamlines procedures for releasing terminally ill inmates, sets strict time-limits to process the requests, and establishes procedures by which the families of terminally ill inmates can help initiate the compassionate release process. However one of the major obstacles to an effective compassionate release programme is the identification of hospices, skilled nursing facilities, and other institutions willing to accept inmates who are terminally ill (MacDougall,1998 :9).

The decision to release a prisoner on medical grounds is thus a complex matter. However in South Africa it is still an issue being debated. The courts appear to be to be in favor of ordering the release of offenders on medical grounds. The Pretoria High Court ordered on 15 March 2004, that a prisoner suffering from leukemia, and according to his doctor was in the terminal stages of the disease, be released immediately, so that he may die at home. The court sharply criticised the Department of Correctional Services for violating the prisoner's right to dignity (Sapa, 2004:3). In yet another court case the Pretoria High Court ordered the immediate release of a convicted murderer, who was sentenced to life imprisonment, from prison as he was suffering from AIDS (Sapa, 2005:4). In giving judgement the judge said that refusing to release the offender would be unjust, unlawful and unreasonable. According to the 2003/2004 Annual Report of the Inspecting Judge of Prisons, on 4 August 2003 the Cape High Court had also ordered a prisoner to be released from prison on medical evidence that he had three to nine months to live due to inoperable lung cancer. However, the medical release of HIV/AIDS sufferers is a complex issue and each case needs to be considered in totality before coming to a decision. By contrast the Msunduzi Hospice in Pietermaritzburg in July 2004, revealed that in their experience prisoners who die in prison die with dignity, compared to the hundreds of dying people in the community who have nobody to care for them, or who have families who cannot provide adequate care for them, or afford the meals and medication required (Interview with Snowden: Msunduzi Hospice: 2004).

These comments should be seen in the context that the majority of prisoners in South Africa come from a sector of the population who are already disadvantaged socio-economically due to unemployment and poverty. The release of a terminally ill prisoner into the care of such a family places an added burden on a system that is barely coping to provide for its own needs. The complexity of factors to be considered when releasing prisoners on compassionate grounds can be seen in the figures of medical releases that were recorded in South Africa over the last few years. According to the 2003/2004 Annual Report of the Inspecting Judge of Prisons in South Africa, during 2003 only 117 (7%) of terminally ill inmates were placed on medical parole. The above scenarios prove that the issue of medical releases of offenders is a complex matter, which has to be looked at in conjunction with socio-economic factors in the community. It is dependent on a variety of issues specific to the individual and his/her family and cannot be looked at in isolation. These scenarios are, however, a reality that is played out daily in correctional centers across the world.

## **2.16      Serving Dying Patients In Correctional Centres**

Dealing with death is a pivotal part of the palliative care continuum and is thus important to this study.

With longer sentences and limited use of medical parole and compassionate release, the number of terminally ill inmates is expected to grow (Ratcliff, 2002: 1) This places a tremendous challenge to correctional institutions to put strategies in place to deal with larger numbers of offenders who will be dying in prisons.

Some 3000 inmates die in United States prisons each year, many of them from terminal illnesses and most under conditions that many hospice professionals would view as challenging (Beresford, 2004:2). As discussed earlier in the literature review more people are dying of AIDS in prisons in South Africa. Caregivers thus have to deal with an increasing number of offenders who are dying in prisons.

Internationally there are two primary factors for the increase in prison deaths, namely, the prevalence of HIV infections in prison populations, and the imposition of longer prison sentences as a result of tougher sentencing laws (Thigpen & Hunter, 1998:4). These reasons are applicable to the South African situation as well.

### **The Grief Of A Dying patient**

Often unappreciated is the fact that the dying patient may also be grieving. The patient anticipates losing all the people he leaves behind. He also anticipates losing his work, his pleasurable activities, and everything he holds dear (Blacher, 2004: 8). It is thus important for caregivers to acknowledge this grieving process that the dying patient undergoes.

### **Preparing For Death**

Inmates dread dying in prison. They fear spending their last hours in agony, alone, separated from family outside and from friends within prison walls. Yet those worst dreams can come true globally for thousands of prisoners a year (Byock, 2002:1).

It is often believed that it is not appropriate to talk about death as this may hasten the process. However for those people who wish to discuss death, open discussion, ideally from early diagnosis, can help dying people to feel that their concerns are heard, that their wishes are followed, and that they are not alone. The period of living we call "dying" holds important opportunities for communication, for completing relationships, even reconciling strained relationships between family members, former spouses, or close friends. There is also a chance to tell one's stories and review one's life, to make a unique contribution to the family legacy, and for those around the dying person to listen and receive, to affirm for the dying person the value of their being and their story. And there is a chance to explore soulful and spiritual aspects of life, those deeper questions of meaning and the connection inherent in the human condition (Byock, 2002:5).

This situation, that is, preparing for death as early as possible after a life threatening illness is diagnosed, is called anticipatory grief (Reder, 2003: 329). Anticipatory grief includes changing assumptions, adapting to role changes, whilst at the same time experiencing feelings of sadness, depression and anxiety. Patients and caregivers suffer from loss of health, security, employment, relationships, meaning and the future. As the disease progresses, the losses increase and intensify. Facing these losses can be overwhelming for all involved (Reder, 2003: 329).

Facing anticipated losses can be even more overwhelming for offender-patients because of their separation from families, the restrictions placed on them by virtue of their incarceration and the uncertainty surrounding their timeous release from prison. The possibility of dying in prison away from their loved ones can evoke strong feelings of fear, anxiety, helplessness and hopelessness.

Most people want to know that they will be remembered. Encouraging family and friends to share stories or memories of the person's life makes the person feel loved and cared for. People who are nearing death are frequently afraid of dying in great pain. They need to be assured that pain relief will be carried out to the point of death. Patients may also worry about dependants, partners and children. Making plans can reduce anxiety and making a will can prevent family conflict and ensure that partners and children are not left destitute (Reder, 2003: 329).

There may be several issues that a dying person may want to discuss and resolve prior to succumbing to death. Some of the practical issues that a dying person may wish to discuss are:

- Custody of children
- Family support
- Making a will
- Funeral costs
- Future school fees

People who are dying may also experience many emotional issues that may require resolution in order to allow the person to die in peace. The following are emotional issues that may be discussed before death:

- The need to resolve old quarrels and make peace with the people involved.
- The need to inform family members that they are loved.
- Sharing hopes for the future especially for children who are left behind.
- Dealing with fear of dying.
- Bidding farewell to caregivers, providers and family

(Blacher, 2000: 7)

Preparing for death is a complex but necessary process, which allows the dying person to deal with unfinished business and go in peace, and helps the family in the bereavement period that follows. It is therefore an important part of the palliative care model.

## **2.17 Conclusion**

The HIV and AIDS pandemic has moved past the infection stage of the disease to more people being in the final stages of the disease and approaching death. The strains of coping with this in communities and in prisons are a challenge. Models of care highlighting the need for a continuum of care and the specific focus of care at the various stages have been developed. Palliative care has been introduced for caring for HIV/AIDS people in the community and in correctional settings.

These have many implications for service delivery. There are many challenges in implementing it, especially in the context of prisons.

# CHAPTER 3

## RESULTS AND DISCUSSION

### 3.1 Introduction

This chapter presents the results and discussions of the present study in five sections. Data was collected using a combination of methods. The following issues emerged as broad themes:

- Description of sample characteristics
- Palliative services provided and perceptions of the services by the offender-patients
- Challenges that staff and offenders experienced in the delivery of palliative care services
- Recommendations to improve services by respondents in the study.

### 3.2 Sample Characteristics

The sample comprised of seven male offender-patients who were terminally ill with AIDS at the prison hospital at Medium B Correctional Centre, which is situated at Durban Management Area. The following issues will be discussed under sample characteristics:

- Age and marital status of respondents
- Crime profiles of respondents
- Medical details of respondents



### 3.2.1 Age and Marital Status of Respondents

The following table sets out information of the respondents in terms of age and marital status:

**Table 2: Ages And Marital Status Of Respondents**

Participant	Age	Marital Status
1	27	Single
2	35	Single
3	38	Single
4	28	Single
5	29	Married
6	44	Married
7	27	Single

According to table 1, five of the respondents were single. All the respondents fell in the age range between 27 and 44 years. According to Reder (2003: 329) as discussed in the literature review, patients suffer from loss of health, security, employment, relationships, meaning and the future when diagnosed with a life threatening disease. These losses are felt much more by patients who are in the prime of their lives and have many unaccomplished goals. This was illustrated by the response of one of the participants who stated that, "I don't want to die now. I have too much to do still."

Facing these losses can be overwhelming, especially for offenders who are not free to plan and make up for anticipated losses.

In offender-patients these feelings of fear, anxiety, helplessness and hopelessness are intensified as they could be blaming themselves for acquiring HIV/AIDS as retribution for the crimes that they committed. In addition they are marginalized and have to face the double stigma of society as criminals as well as having a disease which carries society's prejudice.

### 3.2.2 Crime Profiles of Respondents

**Table 3: Crime Profiles of Participants**

<b>Respondent</b>	<b>Date of sentence</b>	<b>Sentence</b>	<b>Crimes Committed</b>
1	12/09/2003	3 Years imprisonment	1. Possession of firearm 2. Possession of ammunition
2	13/05/2002	8 years and 721 days imprisonment	1.Theft of motor vehicle; 2.Parole break
3	16/04/2002	15 years imprisonment	Murder
4	28/09/2000	18 Years imprisonment	Rape
5	25/06/2004	15 Years imprisonment	1. Two Counts: Possession of stolen vehicle 2. Bribery and corruption
6	11/02/2002	6 Years	Indecent assault
7	2/03/2004	20 Years	1. Three counts of attempted murder 2. Robbery with aggravating circumstances

In this study the records showed that four of the seven respondents spent periods of between one and four years awaiting trial in prison prior to being sentenced. Three of these participants were diagnosed HIV positive whilst awaiting trial in prison. The medical files reflected that they received medical treatment both whilst awaiting trial and after having been sentenced. It is encouraging to note that the offenders had access to medical treatment during the different stages in the sentencing process.

The remaining three respondents were admitted to the prison hospital in the year that they were sentenced. This suggests that they could have been already ill at the time they were sentenced and admitted to prison. This places a serious burden on the Department of Correctional Services, as prisons do not have adequate health care facilities and resources. It is difficult to provide the intense and specialized care needed by terminally ill patients in prisons. It also results in additional costs to the Department of Correctional Services budget and according to staff in the focus group this increases the workload of an already overworked staff.

Four of the respondents in the study were transferred to the prison hospital at Durban Management Area from prison hospitals across the province of KwaZulu-Natal. As discussed in the literature review (Chapter 2,40) one of the principles of palliative care is that a coordinated, continuous plan of care is maintained from the time of admission to bereavement and support of the family. In this study the medical records reflected that medical services rendered at the transferring hospitals, were followed through at the prison hospital at Durban Management Area, thereby ensuring continuity of treatment. As discussed in the literature review (Chapter 2, 42) one of the principles of palliative care is that a coordinated, continuous plan of care is maintained from the time of admission to bereavement and support of the family.

According to the crime profiles (Table 2) the offender-patients were sentenced to periods of imprisonment ranging from 3 years to 20 years. The crimes that they were sentenced for ranged from parole break, theft of motor vehicle to murder and rape. Two of the respondents who were sentenced in 2004, less than a year prior to the study, were already terminally ill. This means that they had not had the time to adjust to being imprisoned and to work through possible feelings of guilt about the crime, or to deal with unfinished business in their personal lives. One can argue that the primary purpose of rehabilitation is being defeated in this situation. They have committed serious crimes and have been sentenced to long terms of imprisonment, that is, 15 and 20 years respectively. Circumstances such as these pose many dilemmas for the South African criminal justice system and for the Department of Correctional Services. The questions that can be asked are: What are the legal and social implications of alternate sentencing for persons who are ill with HIV and AIDS and have committed serious crimes? Should the justice system be looking for alternate community based sentences for these offenders? Should the illness be taken into account as a mitigating factor by the courts during the sentencing process?

As discussed in the literature review (<http://www.aegis.com/news/ads/2001>) (Chapter 2, 27) the justice system in other countries do not consider HIV or AIDS as a mitigating factor during sentencing. The situation in South Africa appears to be similar. Discussions with an advocate in the Pietermaritzburg High Court revealed that the South African justice system as a rule also does not consider HIV or AIDS as a mitigating factor during sentencing for two reasons. Firstly, the court has to consider the interests of society, the seriousness of the crime and the interests of the accused in passing sentence. Secondly, the court believes that prisons have the necessary medical facilities to care for the sick person. (Personal interview: Advocate Blumrick: Pietermaritzburg High Court: 14/09/05).

### 3.2.3 Medical Details Of Participants

**Table 4: Medical Details of Participants**

PARTICIPANTS	DETAILS OF MEDICAL CONDITION OF PARTICIPANTS
1	Admitted to prison hospital in September 2004. Has developed paralysis in his right leg due to a stroke; suffers from weakness in his knees; walks with crutches.
2	His condition is deteriorating; has received treatment for TB but defaulted with treatment regularly. Was referred to Wentworth Hospital for specialist treatment.
3	Diagnosed to be HIV-positive in 2002. Suffers from TB. Was transferred from Kokstad prison hospital to Durban prison for treatment 3 months ago. Has been referred to an external hospital for X-Rays.
4	First became ill in November 2003. Admitted to Waterval prison hospital, but asked for a transfer to Westville as he believed he will receive better treatment. He was transferred as requested, but is still not happy with his treatment and has asked for a referral to an external hospital. Suffers from massive glands, his legs are affected and he is extremely weak. Uses a wheelchair.
5	Initially admitted to Eshowe prison; transferred subsequently to Durban prison for treatment. Is HIV-positive and receives treatment for TB; is extremely weak. Walks with crutches.
6	Diagnosed HIV-positive in 2002. Was transferred from Ncome prison to Durban in early 2003 to be near his family. He also suffered a stroke and suffers from hypertension. Walks with crutches; his condition is deteriorating.
7	Diagnosed HIV-positive in July 2002 whilst awaiting trial. Received treatment for TB but defaulted treatment from October – December 2002 because he felt better. Counselling about compliance. During 2003 he remained terminally ill with a poor appetite, recovered slightly during early 2004 when he was able to walk with crutches. At the time of the interview he was totally bed-ridden again.

\* all the above information was transcribed directly from the medical files.

According to the treatment and care model (Chapter 2 Page 35) services for voluntary counselling and testing should be made available at the asymptomatic stage. According to prison policy all offenders have access to this whilst in prison. All the respondents confirmed that they received pre-test and post-test counseling during the testing phase.

It is clear from the contents of the medical records (table 3) that four of the respondents suffered from tuberculosis, an HIV related opportunistic infection. Also, it can be inferred from the above medical records of the respondents that the roller coaster nature of the HIV and AIDS disease was evident.

The patients suffered from declining health alternating with periods of stability, which is considered normal in the course of the disease as discussed earlier in the literature review (Chapter 2; Page 47). The mobility of the offender-patients had also deteriorated because of the disabling nature of the illness.

According to the medical profiles many of the respondents had developed complications requiring specialized care. The prison hospital does not have the resources for specialist care. According to information from the files there were plans to refer these offender-patients to provincial hospitals for specialist care.

### **3.3 Care Services And Perceptions Of The Care Services**

#### **3.3.1 Physical Environment**

The context in which care takes place plays an important role in the quality of care provided and on the morale of both patients and staff.

Health care in the Department of Correctional Services is practiced within a hospital setting within the confines of the prison (B-Order Ch 3 S.12.).

In terms of section 7(2)(b) of Correctional Services Act, No 111 of 1998 male offenders must be accommodated separately from female offenders. This stipulation of the Act, No 111 of 1998, also applies to provision of services within the prison hospital.

From observations and discussions with staff, it was noted that the hospital presently accommodated only male offender-patients, which was in accordance with the provisions in the above-mentioned Act. Female offender-patients were treated in cells within the female prison. According to staff in the focus group, a newly built ward for female offenders had been attached to the prison hospital at Medium B Correctional Centre. However this ward was not operational at the time of the study due to staff shortages.

Once operational this ward will have the capacity to accommodate fourteen female offenders who will require care services twenty- four hours per day. Accommodating both male and female offender-patients under one roof is an example of the shift in policy of the correctional system in South Africa in order to meet the needs of patients and maintain their dignity. It is also a way of reducing the costs of medical care, for example, by maximizing the use of equipment.

The researcher observed that the hospital wards were spacious and painted a pleasant cream color. It was also observed that the new female wing was painted pink and was equipped with television sets. According to the staff the colors were carefully chosen based on color theory. According to the literature different colors signify and promote different feelings ([www.color-wheel-pro.com](http://www.color-wheel-pro.com)). Emphasis was placed on colors that signify healing, romance, love, friendship, intellect, freshness and joy. These colors were traditionally not allowed in prisons, which usually tended to be grey and drab. The researcher observed also that the wards had artificial ventilation, which circulated the air constantly and removed odours, leaving the hospital fresh and odour free. It can thus be deduced that the built environment within the hospital facilitates the provision of palliative care to an extent.

Efforts have been made to improve the quality of care. The researcher observed that there were panic buttons in the wards, which the patients could use to summon the nurses when in crisis. Patients were more than satisfied with this service as it enabled them to seek help when needed, “ I am happy because I can call the nurse if I need help.” This service allows for some individualized and immediate assistance being available to sick offender patients. This service is comparable to those in wards of provincial hospitals.

It was observed that some patients wore their own clothing. Others were provided with clothing issued by the Department of Correctional Services, which were pleasing to the eye in pale blue and white. This does allow the patient-offender an element of choice, which is a significant element of palliative care.

The compromises to prison policy discussed above, confirm that the Department of Correctional Services is ensuring that a caring and humane environment is provided to terminally ill AIDS patients whilst in the prison hospital.

### **3.3.2 Care Services**

Data on available care services and the perceptions about the quality of these services were obtained from the semi-structured interviews with seven offender-patients, and focus group interviews with staff and the AIDS Control Committee.

The biographical data presented in Table 4 is relevant to the discussion on care services:



**Table 5: Area of Residence, Religious Affiliation, Next of Kin and Culture of Respondents**

<b>Respon- dents</b>	<b>Area Of Residence</b>	<b>Religious Affiliation At Admission</b>	<b>Next Of Kin</b>	<b>Culture/ Ethnicity</b>
1	Umlazi Township Durban	Zion Christian Church	Mother	Zulu speaking
2	Umlazi Township, Durban	No Church or Faith	Uncle	Zulu speaking
3	Marianhill	Roman Catholic	Mother	Zulu speaking
4	KwaMashu Township, Durban	Presbyterian	Mother	Zulu speaking
5	Mandini, Stanger	No Church or faith	Wife	Zulu speaking
6	Verulam	No Church or faith	Wife	Zulu speaking
7	Pinetown	No Church or Faith	Mother	Zulu speaking

According to the respondents and review of prison policies and records, the following palliative services were available to patients terminally ill with AIDS:

- Services by internal service providers, namely:
  - Medical and nursing services
  - Social work services
  - Religious care services
  - Psychological services
- Specialist services
- Services with medical assistance devices
- Nutritional services
- Services that facilitate medical releases
- Volunteer services
- Culturally relevant services
- Services that promote family contact and support
- Services that promote complaints and requests by offenders, a service that is relevant to the correctional context.

The above-mentioned services will be discussed in greater detail below:

### **3.3.2.1 Services by Internal Service Providers**

The integrated team within the palliative care model (Chapter 2,50) presents a model of the various role players that should be ideally available for the holistic care of patients and families. Presently, doctors, nurses, social workers, religious care workers, chaplains and custodial officials are employed by the Department of Correctional Services to provide services to offenders. They can therefore become an integral part of the patient and family's support system throughout the care process.

The access and perceptions to the services by various internal service providers will be discussed below:

#### **Medical and Nursing Services**

All the research participants had contact with the prison doctor and nurse. This reflects an emphasis on the medical model of care, which might be necessary because of the nature of the illness of the respondents. According to the nurse in the focus group interview the doctor came in daily at around 11h00 and left at approximately 14h00. He attended to offenders on both an in-patient and out-patient basis during this time. In the hospital he only attended to patients who were referred to him by the nurse.

Self-referrals by the patients were not accommodated. Another doctor came in at 14:00 but only attended to emergencies. The system adopted cheated the patients of an element of choice, as they had no access to the doctor unless the nurse referred them.

The research participants had different perceptions about the nursing services. Some of the responses were:

- "Nurses have no time to talk to us".
- "Nurses should show more interest in their work and provide better care for the patients."
- "Nurses try their best to do their job," acknowledging that nurses are overworked and burnt out by the very nature of their work with the sick and dying patients.
- "The nurses should spend more time with patients instead of sitting in the office." They preferred the nurses to display more caring by speaking to each patient daily at least.

Whilst some respondents acknowledged the attempts by the nurses to provide an adequate service, others were quite clearly not satisfied with these efforts.

### Social Work Services

According to literature review the goal of social work in palliative care is to help the patient and family deal with the personal and social problems of illness, disability and impending death, and to provide survivor skill-building and support (Kutzen, 2003:449). Only two of the respondents had contact with a social worker and this contact was specifically for medical release purposes. According to the social worker in the focus group discussion social workers previously rendered individual counselling sessions to patients, consultation sessions with family and support groups for patients in addition to investigations for medical releases. Staff shortages at the time of the research had resulted in social work services being limited to medical release applications only.

The positive aspect of medical release investigations was that the nurse and social worker worked as a team in visiting the family to determine their suitability to care for the patient and the conduciveness of the home environment for patient care. Whilst a social worker's visit to an offender's family was generally restricted to emergency situations only, family visits were a norm when dealing with the medical release of a patient.

### Religious Care Services

The need for religious care is a vital component of the treatment and care model as discussed in (Chapter 2, 35). These services also form an important part of palliative care. As discussed in the literature review Puchalski (2003:290) states that people find great comfort from priests or other spiritual leaders during chronic illness even if they were not actively involved with a church or religious group before their illness. In this study this contention proved to be true as four of the respondents did not belong to a religious denomination when admitted to prison, as reflected in table 4. However all the respondents attended church services or group sessions with religious care workers whilst in hospital.

The research participants generally expressed satisfaction with the availability of religious services, "There are many church services in prison." However they expressed a need for individual pastoral/spiritual intervention, this was reflected in a response of one of the offender-patients " the pastor does not talk to me about how I am feeling."

The personal interaction with a religious care worker might provide the offender-patient with an opportunity to come to terms with feelings of remorse, loss and guilt which are all part of the grieving process as discussed in the literature review (Chapter 2,64).

Since people generally have a need for spiritual care during a terminal illness, Puchalski (cited in O'Neill et al, 2003: 289) has indicated that it is important to include a spiritual assessment as part of the overall clinical assessment of a patient. He states that this would enable the caregiver to assess spiritual needs and resources, mobilize appropriate spiritual care, and enhance overall caregiving. This might be a useful tool in ensuring that the particular needs of the offender-patients are met.

From the above it can be concluded that referring patients to religious service providers is as important as referrals to other specialists. They should also form an integral part of the care team.

During the focus group discussion it was determined that religious care workers from different denominations visit the hospital four times a week, for an hour at a time, for group and individual sessions.

### Psychological Services

According to literature review (Payne & Haines, 2002:15) psychologists form an integral part of the interdisciplinary team as they enable the individual to express thoughts, feelings and concerns relating to illness, and they assess individual needs and resources for coping. Psychologists can also help patients who may feel bitter and cheated about not being able to accomplish their life goals, and who may experience guilt and remorse because of the crimes they have committed.

None of the respondents had contact with the psychologist. Referrals to the prison psychologist were done by the doctor, psychiatrist or by self-referral when needed. At the time of the research there were only two psychologists at Durban Management Area that catered for the needs of approximately 13 000 inmates. Three of the respondents had wanted to see a psychologist. One of the respondent's stated, "I want to see a psychologist to understand more about my sickness, I want to understand what is happening to me." The psychologist in the focus group acknowledged the need to visit the hospital daily, but due to the chronic shortage of psychologists could not see this happening in the foreseeable future.

### Physiotherapy

This service was not provided at the hospital as there was no post for a physiotherapist at the prison. This service is discussed here, however, because the study revealed that five of the respondents made use of medical assistance devices to increase mobility. The patients thus perceived the services of a physiotherapist as being essential to help them to remain mobile and functional. At least one of the research participants who walked with crutches felt that a physiotherapist might assist him to be more mobile. He said, "I'm sure that help from a physiotherapist will make my legs stronger."

### **3.3.2.2 Specialist Services**

As discussed in the literature review Engle (1999:4) indicates that people with HIV and AIDS often need to be seen by other types of specialists for a variety of opportunistic infections, in addition to infectious disease specialists.

According to the nurse at the focus group interview the medical practitioner at the prison refers patients to external provincial hospitals for specialist care. Although this is a costly exercise for the Department of Correctional Services, referrals to external hospitals enabled the prison doctor and nurses to keep in touch with new developments, skills and expertise available at these hospitals. It also served to provide the patient with peace of mind knowing that he had consulted a specialist. The patients were extremely dissatisfied with the limited access they had to specialist services at external provincial hospitals. Some of the comments were:

- “ I am not happy when I can't go to see a special doctor at the outside hospital.”
- “I want to see a specialist at the outside hospital to help me get better. I am not getting better in this hospital.”

Thus the patient's right to choice of treatment was being compromised whilst he awaited this referral to the specialist.

The study revealed that the process was also flawed. Feedback from the external specialist was given in writing. This feedback from the specialist went to the attending doctor in the prison, who in turn passed it down to the nurse who administered the medication. There was, however, no consistent system to ensure that the specialist's recommendations were followed. There was also little or no co-ordination between the specialist and the prison doctor. According to literature (Engle, 1999: 5) this is a problem that correctional facilities across the world are grappling with.

Also, according to the professionals in the focus group, approximately 85% of offenders who were referred to external hospitals/specialists did not keep appointments because of a shortage of custodial staff to escort them. The prison doctor was thus compelled to manage the case without the benefit of a consultation with a specialist.

As indicated above similar problems are experienced in other countries (Engle, 1999: 5), despite attempts at a managed care system. This indicates a need for further research in this area in order to manage this challenge.

To overcome this challenge, legislation of the Department of Correctional Services (Act No 111, 1998: S.12 (3)) makes provision for offenders to consult private doctors at their own cost. This is in line with the principles of palliative care, which provides the patients with an option of choice with regard to their treatment. This can also be a cost saving option for the Department if sick offenders utilize this option. However, none of the respondents in this study used this option because their families were unable to afford the costs of private medical care.

### **3.3.2.3 Services for the Provision of Medical Assistance Devices**

Policies of the Department of Correctional Services made provision for the issue of assistance devices, “ medical assistance devices may only be issued at state expense when there is evidenced medical grounds necessitating the supply thereof on written order of the medical officer/practitioner” (B-Order: S.20.1).

Perusal of the medical records of the offender-patients indicated that the majority of the participants, that is five of the seven respondents, were provided with assistance devices for mobility purposes.

According to information provided by the respondents and from the researcher's own observations, three of the respondents used crutches and one used a wheel chair. The others were able to walk on their own and one respondent was totally bed-ridden. The study revealed that offender-patients have a choice of various assistance devices, for example, crutches, medical trolleys, walking sticks and wheel chairs. According to the staff the doctor approved the use of these devices. The respondents appreciated the availability of these devices, as one respondent said "I am happy because I can move around on my own with the help of the crutches." The availability of these assistance devices allowed for mobility, kept the patients functional and gave them some independence. The results of this study revealed that the policy provisions with regard to assistance devices were well implemented.

### **3.3.2.4 Nutritional Services**

Nutritional management is an essential service to patients who are HIV- positive or have AIDS. Recent research findings (Van Dyk, 1999: 92) have stressed the importance of a healthy diet to enhance the immune response to HIV infection and enhance resistance to opportunistic infections.

According to the nurse in the focus group the diet plan in prisons is compiled by a dietitian and is in line with guidelines provided by the Department of Health.

However the research results revealed that only two of the respondents were satisfied with the meals provided. Some of the complaints by the dissatisfied respondents were:

- " Mealie meal constipates me";
- "I do not like the food but have to eat what I get";
- "The food is not well prepared";
- "Although the quantity is enough, the menu should be changed".



There was also strong dissatisfaction expressed about services to patients who cannot feed themselves. Offender volunteers assisted with the feeding of these patients. Three of the respondents mentioned that patients who cannot feed themselves in the ward often go hungry. This violates the constitutional right of the person to sufficient food and water (South African Constitution No 108, 1996: S.27(1)(b)). This highlights the need to monitor, supervise and control the work of the volunteer offender caregivers to ensure that the above situation does not recur.

During the focus group discussion it was revealed that there are “plans to introduce a food called Philane, a porridge like substance with extra vitamins, which can either be eaten as a porridge or drunk with a straw”.

There are also plans for some high protein diets to be minced to facilitate chewing and swallowing. These plans are laudable and will definitely assist those patients who are critically ill and too weak to chew portions of food. Keeping up with new products in the market is evidence of the Department of Correctional Service’s efforts to improve the quality of life and comfort of patients.

Family members who visit the offender-patients usually brought in fruit, soft drinks, immune boosters and occasionally cooked food during the visit. This encouraged and promoted family responsibility towards the offender-patients and made the patient feel loved and cared for. However, it did pose potential problems in that the nurse complained during the focus group discussion that at times family members brought in the wrong food types, which caused digestive and other problems for the patients. There was thus some degree of conflict between the perceptions of patients and staff in this regard.

### **3.3.2.5 Services That Facilitate Medical Releases**

Medical release, also known as compassionate release, provides a means for early release of inmates with terminal illness. According to literature review (MacDougall, 1998: 12) it is a process that is used by correctional facilities internationally. The Department of Correctional Services legislation (Act No 111, 1998: S.79) states that any person serving any sentence in a prison who is diagnosed as being in the final phase of any terminal disease by the doctor treating that person, may be considered for placement on medical grounds, to die a consolatory and dignified death. Only one of the respondents had a confirmed date for release on medical grounds. This could be linked to the fact that the majority of the participants were newly sentenced.

Two of the seven research participants had applied for medical releases and were awaiting feedback. The process relating to parole approval is time consuming, which is problematic considering that the patients are terminally ill and dying, and do not have time on their side. This means that the lengthy process of medical release might only have started, which could account for the delays incurred in the granting of releases on medical grounds.

The respondent who was bed-ridden and awaiting feedback to his application was obsessed with going home and not interested in treatment, “ I want to go home, I don’t care about treatment.” He expressed anger and resentment at not receiving feedback to his application. The other four respondents had not heard about medical releases and did not know what the process entailed.

A positive aspect of services being provided when considering placement on medical grounds was the visibility of the interdisciplinary approach where the doctor, nurse and social worker worked together.

### **3.3.2.6 Volunteer Services**

The study revealed that volunteer care services were provided by sentenced offenders who were members of the AIDS Control Committee (ACC). The functions and roles of this committee are formalized by the draft policy for Correctional Centre Based Care as mentioned in Chapter one, page 10. This draft policy allows offenders to work as volunteer caregivers. These volunteers were trained in home- based care by St Johns Ambulance and were therefore able to offer the patients quality care.

The work of the ACC is all embracing in that it covers education, training, prevention, support, and palliative care. According to the committee members, the AIDS Control Committee is made up of an executive committee comprising five members and six sub-committees.

According to the focus group interview with the offender volunteers services are rendered by different sub-committees and are amongst others as follows:

- Support and care sub-committee provides spiritual counselling, supportive counselling, palliative care and care for patients suffering from opportunistic infections.
- Social skills and development sub-committee provides opportunities for arts and crafts involvement of inmates and conducts basic research.
- Community safety sub-committee looks at gangsterism and violence in prisons and how these issues may be tackled.
- Education and training sub-committee looks at the provision of training and education opportunities for inmates.
- Support group sub-committee provides support for infected inmates.  
(Focus Group interview)

The ACC offered physical care to the terminally ill offender-patients. One response was, "We change bed linen every day; we change diapers of patients; we bathe and feed patients; we clean windows and floors; we offer spiritual care and counseling as best as we can; we care for the patients and support them, we just sit with them when they don't feel like talking and talk to them when they feel the need to talk."

The ACC also networked widely with external organizations in planning and implementing their strategies, for example, Dream Centre, which provides hospice care in the community, National Association for People Living With AIDS, and religious ministers in the community.

The White Paper on Corrections (2005) allows for interested individuals and organizations from the community who have the appropriate knowledge and skills, to provide volunteer services to offenders. Thigpen and Hunter (1998: 2) confirms that it is necessary to network and form partnerships with non-governmental and community based organizations who have specific skills and experience in palliative care.

On a more positive note the AIDS Control Committee was one way in which the voice of the offenders were being heard, and the skills, expertise, passion and energies of the offenders were being constructively utilized. Utilizing the readily available skills of offenders to complement the provision of services in prison is a cost effective option for the Department of Correctional Services, and a solution to dealing with multiple needs in overcrowded conditions. At the same time it fulfills the rehabilitation objective of the Department of Correctional Services because working as caregivers teaches offenders to be responsible, caring and compassionate. In this way they could also be seen to be atoning for the crimes they committed, that is, the principles of restorative justice are being implemented. Working as caregivers also provided these offenders with a sense of satisfaction and pride at being able to make a difference, "we feel good to be making a difference in the lives of people".

On a negative side the offender volunteers had indicated that, “ we do not get support from prison management and some staff.” Active support from managers especially is crucial to the continued success of this service.

However it is important to consider the offender-patients response to the use of offender-volunteers in providing services to them. Regular evaluation of this voluntary service is necessary to continuously improve the quality of this service. Evaluation forms a vital component of palliative care.

### **3.3.2.7 Culturally Relevant Services**

As discussed in the literature review (Chapter 2,32) palliative care strives to meet the needs of individuals and families with due regard to their personal, cultural and religious values, beliefs and practices. The Department of Correctional Services policies make allowances for the cultural needs of the offenders to be met. One example of this is that the Department of Correctional Services policy (B-Order, Ch 3: S.25) allows for patients to consult with traditional healers in a specified visiting area in the prison. This is an encouraging practice as traditional medicine has been recognized as an important aspect of the treatment and care model (Avert.Org: 2004).

As reflected in table 4 above, all the respondents were Zulu speaking. Four of the respondents believed in the benefits of traditional healing whilst at the same time acknowledging the benefits of western medicine. According to literature ((Eden, 2001:1) traditional treatment for HIV and AIDS can be attractive to patients as they are accessible, culturally appropriate, acceptable and may be more affordable in resource poor communities compared to western medicine. One of the respondents spoke of the personal benefits of traditional medicine, “ I used traditional medicine when I was awaiting trial and it helped me a lot. I could not walk at that time and used a wheelchair. Now I am much better and can walk with crutches.”

The policy, however, prohibited traditional medicine from being taken into prison. This is a double bind situation and a challenge to manage, as the patient's hopes are raised when approval is granted for the consultation, but dashed when he cannot take the medicines prescribed by his traditional healer.

It can therefore be concluded that the patients have difficulty accessing culturally relevant services in the prison environment due to practical problems experienced by staff, prison culture, and policy constraints.

In addition, according to the staff, prison policy allows for the offender-patients to consult with religious leaders of their own faith, thus respecting their beliefs.

### **3.3.2.8 Provision For Family Contact & Support Services**

According to Twycross & Lichter ( 2003: 978) much of the support that a dying person needs can only be given by the family. This is supported by prison policy. Perusal of the medical files revealed that four of the respondents had been transferred from prisons a distance from their homes to the prison hospital at Durban Management Area for treatment and possible release, and more specifically, for purposes of facilitating contact with family, which is also in line with Correctional Services legislation (Act No 111, 1998: S.13(2)).

In this study (table 4) all the families of the offender-patients resided close to the prison, in or around Durban. This close proximity enabled families to maintain contact with the offender-patients. The families resided in urban areas where public transport to the prison was readily available, thus enabling and facilitating visits. All the respondents received visits from family members whilst in prison. All seven of the respondents were satisfied with the process that allowed them contact with their families. Five of them were visited once a month, one, once per week, whilst the other respondent received a visit once every two months. They were also satisfied with the amount of time allocated for these visits to the prison. One response was "I am happy my family can visit me for a long time."

Family members are permitted to visit patients in the wards on days set aside for visiting of sentenced offenders. However, if the patient is in the final stages of a terminal illness the family is allowed to visit at any time on humanitarian grounds. This display of humanity on the part of correctional officials fits in with the care element that is inherent in the palliative care philosophy.

All the respondents indicated that their families provided them with emotional and material support. They provided them with clothing, nutritional supplements, and food. This served to make the patients feel less alienated and more accepted and cared for. Four of the respondents had elderly mothers as their prime source of support whilst in prison. According to the respondents their mothers also pledged support for them should they be released, “ my mother is willing to care for me when I am sent home”.

The respondents were, however, dissatisfied that young children were not permitted to visit in prison for security reasons. A response to illustrate this was, “we are not happy that our children cannot visit us”. As discussed in the literature review (Chapter 2, 64) when patients are terminally ill they have a need to see and talk to children. The children also have a need to deal with certain issues with their parent before he dies.

In terms of the treatment and care model (Chapter 2, 35) the lack of family and child support is a service delivery gap at the prison hospital.

According to Frolich (1996:18) palliative care is family-centred, meaning that both the family and patient are involved in making informed decisions about treatment and care. In this study there was no evidence of support services to family members or involvement of family members in the treatment and care of the offender-patients.

Although the Department of Correctional Services facilitated the family's contact with the offender-patients, a gap in this regard was the lack of support to family members and the lack of their involvement in the treatment and care of the patients.

### **3.3.2.9 Services that Promote Complaints And Requests by Offenders**

Correctional Services legislation (Act No 111, 1998: S.21) allows for staff to visit offenders daily to listen to complaints and requests. These complaints or requests are entered into a register and referred to the relevant persons for attention within a period of seven days. The same policy applies to the offender-patients whilst in hospital.

This procedure provides a channel for the “voice” of the patients to be heard. All the respondents confirmed that an official visited the hospital daily to take their complaints and requests, “A member visits us every day to ask for complaints.” However, all of them complained that they seldom received feedback thus negating the intentions of this service. This lack of action and feedback made the patients feel frustrated, powerless and marginalized. A comment was “What is the point in them taking our complaints when they do nothing about it?” The researcher believes that internal service providers at the prison can play an active advocacy and lobbying role on behalf of the patients to ensure that their rights are not compromised in order to make them as comfortable as possible and give them a sense of hope.

### **3.3.2.10 Leisure And Recreation Services**

The Department of Correctional Services legislation (Act No 111, 1998: S.11) makes provision for offenders to be allowed an hour’s exercise daily, in the open air if the weather permits. However this was denied to patients in the prison hospital. Four of the respondents spoke about the lack of exercise for those patients who were well enough to move around. One response was, “They don’t allow those patients who can walk to go for exercises. Because of that we don’t even see the sun.” The respondents also complained that there were no indoor games or radios or television sets for those who were well enough to enjoy these recreational activities. Thus those patients who were reasonably healthy were also bored and unoccupied.



Offender-patients compared themselves with offenders in the general cells who have access to daily exercises, recreation, and television sets. They thus perceived themselves as having fewer privileges compared to offenders in the mainstream offender population. The question of equality was quite clearly emerging in the comparisons that were being made. However it is encouraging to note that televisions as discussed in point 3.2.1 in this chapter were installed in the new female wing of the prison hospital.

### **3.4 Challenges Experienced in Providing Palliative Care Services In Prisons**

Some of the challenges to provision of palliative care services that were mentioned were:

- **Provision Of Health Care Services in A Secondary Setting**

As already discussed the provision of health care services in a correctional setting poses a real challenge to health workers. According to the nurse in the focus group discussion “the prison hospital does not have sophisticated medical equipment to meet the needs of patients compared to provincial hospitals”.

The challenge is to find a cost effective way of equipping the prison hospital to cater for a small number of offender-patients who would actually need or use these sophisticated services. A further challenge mentioned by the nurse was the need for specialist care for the offender patients. Related to this is the challenge of finding a coordinated cost-effective specialist service between the provincial hospitals and the prison hospital.

Care services in prison are generally available to patients who are in the terminal phase of the disease and who are hospitalized. However, review of literature (Canadian Palliative Care Association, 1995:16) indicates that palliative care may start at a time of diagnosis and becomes more intensive as treatment changes to symptom management, support, and preparation for death. This means that offenders in the initial stages of the disease who are not yet hospitalized are excluded from the care services available.

- **Fear For Safety**

The fear of safety of the staff was also perceived as a challenge. During the focus group discussion the female staff members spoke at length about their fear for personal safety and the impact this has on the delivery of their services. “ We are left alone with large groups of offenders with no male officials around. We do not feel safe.” The nurse who is in charge of approximately fifty patients with varying degrees of illnesses spoke of her discomfort at being left alone with this large number of offenders, some of whom are convicted of aggressive and violent crimes and are serving long sentences. “Many patients are well enough to be walking around and could pose a risk to my safety.” The social worker and psychologist both expressed similar feelings of disquiet at being exposed to offenders who are classified as high risk, “ We all feel unsafe, but nobody cares about how we feel.”

This concern for personal safety may be linked to the recent escapes at the prison and the hostage taking of a social worker during the escape, and may therefore be justified, “We feel worse after the escapes and have a problem focusing on our work.” According to O’Neill et al (2003:413), caregivers may be burdened by work-related stressors in addition to stressors brought about by caring for dying patients. In this instance fear for personal safety appears to be a primary work related stressor.

- Overcrowding

Overcrowding at the prison impacts directly on the provision of quantitative and qualitative services to offenders. During the focus group discussion the professionals complained about the impact of overcrowding on the quality of their work. Systems had been put in place to avoid overcrowding in the prison hospital. According to the nurse "there is a special cell in section C3 in the prison where offenders who require chronic medication are housed.

But because of overcrowding in this cell (approximately 70 inmates occupy this cell built for 40), there is a spillage into the prison hospital, which is intended to primarily provide care for the terminally ill patients."

In the researcher's opinion overcrowding also poses a challenge to the containment of infections within prisons.

- Difficulty in Recruiting Staff

Although the Department of Correctional Services has recognized the need to employ more staff they have difficulty in recruiting staff. During the focus group discussion with staff it emerged that there were forty two vacant posts for nurses at the hospital. This comprises 72% of the total staff complement.

Only two posts for psychologists were filled. These two psychologists serve approximately 3000 offenders in Medium B correctional centre where the hospital is located, and approximately 13 000 inmates within Durban Management Area. The social worker also cited shortage of staff at the focus group discussion as a reason why regular services were not being offered at the hospital.

The filling of these vacant posts expeditiously is a major challenge to the department as it impacts directly on the nature and quality of services being rendered (Focus group interview). However, this problem is not unique to the prison but endemic in the general public health sector in South Africa, which has 31% of all its health posts vacant at this point in time (Govender, 2004: 5).

- **Interdisciplinary Team Approach**

The interdisciplinary team approach is crucial to the provision of palliative care services in its entirety. During the focus group discussion it transpired that staff shortages negatively affected the delivery of social work and psychological services to patients. Where different professionals were involved in the provision of services, for example medical services and religious care services, each came in at different points and exited after providing the service. There was, thus, a glaring absence of case management, team discussions and team decisions about the management of cases. The building of a trusting and respectful relationship between team members and the patient is central to the philosophy of palliative care as discussed earlier (Chapter 2, 40).

Since palliative care is about attending to the holistic needs of the patient, the challenge lies in ensuring that the various professionals work together as a team. As the nurse indicated during the focus group discussion, “ we have to work together for the sake of the patient.” According to literature review (Kutzen, 2003:447) the complexity of AIDS in all its dimensions requires this type of comprehensive, collaborative, and multi-leveled response from professionals.

- **Medical Release**

With regard to the medical releases of terminally ill patients the real challenge lies in managing the release of these patients in time to allow them to die in dignity within the comfort of their homes and surrounded by loved ones. According to case records at the prison hospital, applications for medical releases were submitted on behalf of thirty five terminally ill patients from January to October 2004. Thirty two patients died before their application was approved, one application was disapproved and two applicants were successful. The offender who is terminally ill has the right to die in dignity amongst family in a loving home environment. This right, however, has to be balanced against the right of the members of the community to protection from criminal elements. This is a major challenge that confronts staff at the Department of Correctional Services.

A further challenge mentioned in the literature review (Chapter 2, Page 60) was that families were generally unwilling to care for their loved ones who were ill with AIDS. However, in this study the families of all the respondents were willing to care for them upon release. It must be noted that there is a difference between the families' *willingness* to care for their loved ones and their *ability* to do this satisfactorily based on their circumstances and socio-economic situation. Therefore an individual holistic assessment is needed prior to the decision to release the patient on medical grounds.

- **Prison Culture**

If the Department of Correctional Services is to provide appropriate and effective palliative care for persons with HIV/AIDS, it is important to have an understanding of the cultural context within which such care will be provided (Sandoval, 2003:301). The culture in prison is largely influenced by an institutional environment, which demands the survival of the fittest and strongest. According to the Department of Correctional Services Concept Document on Rehabilitation (2003: 4) offenders in prison live by a different moral code and different set of values compared to society at large.

Offenders become desperate to overcome the effects of institutionalization by focusing on having control over their environment and they may use manipulation to achieve their goal (Concept Document on Rehabilitation, 2003: 4).

During the focus group discussion the nurse mentioned that food is often used as a commodity for trading in prison, "Some patients who are on therapeutic diets sell their food in return for tobacco." According to the staff trading food for various commodities is part of the prison culture; so is stealing from each other. Three of the respondents complained that offenders who worked as cleaners in the hospital stole personal belongings from the patients. One participant said, "Cleaners help to bathe patients but rob them of personal things;" another said, "Cleaners steal personal stuff from patients who go to the bathroom."

Changing the culture in prison where positive values, norms, morals and behaviour is embraced is a major challenge for the Department of Correctional Services. This aspect needs attention if the offenders are to return to society as rehabilitated persons. Rehabilitation is one of the primary objectives of the Department of Correctional Services in South Africa (Strategic Plan 2005/2006).

- **Provision of Antiretroviral Therapy**

Anti-retroviral therapy improves the quality of life of patients who are suffering with HIV/AIDS. The provision of antiretroviral therapy is an integral part of the treatment and care model but is a challenge in prisons at this point in time.

According to the nurse in the focus group discussion, “there are no clear internal guidelines to help us to administer antiretroviral therapy and supplies of antiretroviral drugs are not available”. Only patients who started antiretroviral treatment before admission to the prison may still access therapy from their initial service point.

In this instance supplies of the drug are obtained from the community clinic or hospital that started the offender-patient on the treatment. The World Health Organization’s equivalence rule states that health services that are available in the community must be available in prisons as well. Presently there are several health clinics in communities that are administering antiretroviral drugs. The challenge is to ensure that this therapy is available in prisons as well.

- **Traditional Healing**

Allowing offenders’ access to traditional healers was perceived as a challenge by staff, although prison policy made provision for consultations with traditional healers. During the focus group discussion the nurse felt strongly that allowing traditional medicines into prisons could complicate the treatment of patients, “We don’t know the quality and content of the traditional medicine, and cannot test what the family is bringing in; this is risky for the health of the prisoner. Should something go wrong with the prisoner we will be held responsible”. She further indicated, “patients may react to the unknown contents of the medicine, these

medicines could be stolen by other patients, and as nurses we are not allowed to store or dispense traditional medicines”, indicating some of the challenges that can be experienced in this area.

- **Adherence To Medication**

The prison hospital utilized directly observed therapy (DOT) to dispense medication. According to information obtained during the focus group discussion this was a major challenge. The nurses dispensed this medication and patients swallowed the medication in their presence. According to the nurse, patients did not always swallow the tablets as at the end of a day there were dozens of tablets lying on the floor against the walls at the out-patient section. The medical files of two of the respondents reflected a tendency to default with TB treatment, despite counselling on the benefits and necessity of compliance. Compliance to prescribed treatment and adherence to medication is thus a challenge that needs to be creatively managed for the recovery process to be successful. Maintaining of confidentiality when dispensing medication poses a further challenge in prisons because of the overcrowded conditions.

In the community counselling with regard to complying with DOT includes family members. This process is likely to be more successful at home because of the support from family. This support is not available to patients in the prison hospital, which is yet another challenge.

- **Universal Precautions**

It is generally known that adult HIV infection occurs as a result of sexual contact, or when there is contact with infected blood. Therefore the principle of “universal precautions” must be followed at all times. The Department of Correctional Services HIV and AIDS in the workplace document states that all people (officials and offenders) involved in any situation where the danger of contamination with the HIV virus might exist, must be provided with the equipment to protect themselves, that is, latex gloves, surgical gloves, etc.

Members of the AIDS Control Committee provide volunteer care services to patients who are terminally ill with AIDS. They complained that infection control and universal precautions do not apply to them as offender caregivers. They are not given any protective clothing or disposal gloves.

The challenge is to ensure that universal precautions apply to both formal caregivers (staff) and informal caregivers (offender volunteer caregivers), as reflected in the HIV and AIDS workplace document.

- **Difficulty In Implementing Restorative Justice**

Another dilemma that was mentioned during the focus group discussion with the staff was the need to adhere to restorative justice principles and feelings of victims when considering sentencing of the offender and the early release of offenders on medical grounds. Restorative justice is an approach that has been adopted by the Department of Correctional Services and is based on the concept of forgiveness and healing. One of the terminally ill participants was sentenced for rape only two years ago. The short time between sentencing and becoming ill does not allow for healing and forgiveness to take place, for both the victim and offender. In all probability this respondent was already HIV-positive when he committed the offence. What has happened to the victim? Has the victim suffered from trauma for the rape and is also now HIV-positive and having to deal with this “death sentence?” What about the respondent’s own feelings of guilt at committing the offence? Thus in the prison context, specific philosophies and principles are difficult to implement when a terminally ill person is admitted to the prison system.

- **Care For Caregivers**

According to literature review (O’Neill et al, 2003: 25), the unpredictable course of the HIV disease and the death of young patients can create significant stress and burden for caregivers. It was clearly evident from the focus group discussions with both the AIDS Control Committee and members of the interdisciplinary team that care for caregivers is recognized as being necessary



but nonexistent at the prison. This challenge needs to be urgently addressed to avoid burnout and depression on the part of staff and volunteer caregivers.

- **Burials of Deceased Offenders Whose Families Cannot Be Located**

Our human response to a dying person may be sadness at the loss or a sense of failure at not being able to stop the fatal disease (<http://www.lifethreat.org>: 7).

The usual course of events when a loved one dies is for the family to perform their last rites and rituals. This helps them with the mourning process and to come to terms with the loss.

According to the nurse in the focus group discussion the family of the deceased patient claims the body from the funeral services for burial purposes. The family is responsible for the burial costs. At times family cannot be located at addresses given. The South African Police Services and the internal social workers then attempt to trace the family. A notice can also appear in the media for the family to contact the Department. This process can at times take a period of six months to finalise, thus impacting on the dignity of the deceased person to be buried as soon as possible. According to the nurse in the focus group interview, the Department of Correctional Services accepts responsibility for the burial should the attempts to trace the family yield no results. The nurse further stated that at times the family refused to claim the body due to financial constraints or fear of stigmatization from the community. When this happened the Department also accepted responsibility for the burial. Managing this situation is a real challenge to the Department on two levels, namely, deceased offenders have a right to be buried as soon as possible, and, secondly involvement of families help to bring about closure. Family support is an important aspect of the end stage of the treatment and care model.

### **3.5 Suggestions To Improve Delivery Of Palliative Care Services To Terminally Ill patients At The Prison Hospital**

The offender-patients' who were interviewed during the study and participants of the two focus groups comprising staff and offender volunteers, mentioned several issues that needed attention to ensure the rendering of satisfactory palliative care services at the prison hospital. These issues will be discussed under the following broad categories:

- **Filling of Vacant Posts in the Prison**

There was consensus amongst both staff, offender volunteers and offender-patients that the vacant posts for professional staff, for example, nurses, social workers, psychologists, and resident doctors needed to be filled as a matter of urgency, as it impacted negatively on the rendering of services at the hospital. It also contributed to burnout on the part of existing staff as they had a bigger workload to carry. Efforts should also be made to employ an aggressive retention strategy to prevent the drain of professional staff from the Department.

Further suggestions to improve service delivery in the current situation where many posts are vacant were:

- Employment of nursing assistants to complement the nursing staff. Posts for auxiliary nurses could be re-instated as their appointment will enable the registered nurses to focus on clinical patient care, rather than auxiliary services.
- Offender volunteers need to be trained and provided with resources, support and access to safety equipment like latex gloves, masks, etc in line with the principles of universal precautions. These principles should apply to both staff and offender caregivers.
- A creative balance needs to be created between the requirement for the safe custody of offenders and the escorting of patients to external hospitals for specialist care to ensure that both needs are prioritized.

- Measures need to be put in place to ensure the safety of female staff as the study revealed that the fear for personal safety also impacts on the services delivery.
- Measures need to be put in place to ensure that security considerations do not disrupt the work of offender volunteers at the hospital. Structures need to be established to ensure that the offender caregivers are escorted daily from their cells to the hospital to enable them to undertake their responsibilities.
- The Specialist clinic: staff recommended the establishment of a specialist clinic at the prison hospital to promote integrated service delivery.
- Antiretroviral Therapy  
The staff recommended the following:
  - The development of clear internal guidelines with regard to the provision of antiretroviral therapy.
  - Negotiations need to be undertaken with the Department of Health to ensure the prison hospital is accredited to provide antiretroviral therapy to offender-patients.
- Revisiting of Policy relating to Traditional Healing  
Offender patients wanted traditional medicines to be made available in prisons. The Department of Correctional Services policy therefore needs to be re-visited as it allows for consultations with traditional healers but does not permit the storing/taking of traditional medicine after the consultation, thereby creating a dilemma for patients. This needs to be done in accordance with broader South African legislation in this regard.
- Revisiting of policy and procedures relating to medical releases to ensure speedy releases of terminally ill patients in line with international practices.

- Provision of initial bereavement counselling to families of deceased offenders and referral to external service providers for continued services thereafter.
- Nutrition: Making the meals look more appetizing, for example, additional spices could contribute to the aesthetic value of the meal, making it more appealing to the palate.
- The introduction of leisure activities at the hospital. Offender-patients wanted “radios, television sets and indoor games” in particular. Those patients who were able to walk “asked to be taken outdoors once a while to be able to enjoy the sunshine”.

- Support From Management

Both staff and offender volunteers felt that active support from management is needed to ensure success in delivering palliative care services at the hospital.

Support from management was required in the following areas:

- In acknowledging, supporting and providing incentives for the work done by the volunteer caregivers.
- In creating a balance between security considerations and the work of the professionals to enable latter to be able to do what is required of them as well.
- In providing the necessary resources in terms of human resources, transport, finances, etc.
- In buying in to the need for palliative care services and acknowledging its necessity when working with terminally ill patients.
- In the taking of decisions in consultation with professionals when these decisions impact on their work.

- Care For Caregivers

A system to provide support, debriefing and prevention of burnout has to be put in place urgently, as the chronic shortage of professional staff further exacerbates the normal burnout that is experienced when working with terminally ill patients.

- Training for staff on palliative care

All staff, especially the nurses need to be trained in palliative care, as this will enable them to respond more appropriately to the needs of the terminally ill patients.

### **3.6 Conclusion**

It can be concluded that some elements of the palliative care approach and philosophy are visible in the care services that are available at the prison hospital. There are many challenges that impede the provision of this service in a prison setting. Interesting recommendations to improve care and treatment to offender- patients have been made by the participants in this study.

## **CHAPTER 4**

### **CONCLUSION AND RECOMMENDATIONS**

#### **4.1 Introduction**

The study ascertained what palliative care services were available for offenders who were ill with AIDS at the prison hospital situated at Medium B Correctional Centre at Durban Management Area. It identified the perceptions of offender-patients about the services they received. The study also identified challenges that staff and offender-volunteer caregivers faced in rendering services within a correctional context in South Africa. The participants in the research made recommendations on how services could be improved.

To achieve the purpose of this study the researcher interviewed seven (7) offender-patients who were terminally ill with AIDS at the prison hospital. The care and treatment programme that offender-patients were exposed to whilst in prison was tracked back to when they were diagnosed with HIV/AIDS. This was done through the content analysis of medical and institutional files. Two separate focus group interviews were held with staff and offender volunteer caregivers. This chapter summarizes the main conclusions arising from the findings, and suggests recommendations on the basis thereof.

## **4.2 Palliative Care Services Available At The Prison Hospital And Perceptions Of The Offender-Patients Of These Services**

According to literature review the prevalence rate of people who are infected with the virus or dying from AIDS in South Africa and globally are on the increase (Chapter 2, 25). The need for palliative care services is thus becoming more necessary. This is also a trend in prisons.

It is important to note that palliative care services for HIV/ AIDS patients at Durban Management Area was regulated by national legislation. The Department of Correctional Services also has policies which guides implementation practices. Amongst the legislation and policies are the Correctional Services Act, No 111 of 1998, the internal policy guidelines (B-Order) of the Department of Correctional Services, the Policy Document: Management Strategy for HIV/AIDS in Prisons, the draft Policy: Correctional Centre Based Care: Offenders as Volunteer Care Givers, and the draft Comprehensive HIV and AIDS Program for Offenders. The Department of Correctional Services subscribes to the World Health Organization's Guidelines for the management of HIV/AIDS in prisons.

As discussed in the literature review, palliative care becomes more intense as treatment changes to symptom management, support and preparation for death. This was evident in this study. All seven of the offender-patients who participated in this study were in the terminal stage of their illness. During this stage their care was hospital based. The Department of Correctional Services attempted to ensure that a caring and humane atmosphere was created at the prison hospital.

This caring and humane atmosphere was evident in that the physical environment was pleasant, with the walls painted in colors that promoted healing, love and caring which is not the traditional norm within a prison. The offender-patients were allowed to wear their clothing of choice. Attempts were also made to provide individual attention to patients by the use of panic buttons to enable them to summon staff when in need.

In terms of the treatment and care model discussed in Chapter 2, 35), certain services are needed at the different stages of the progression of the HIV infection. The content analysis of patient-offender files and the responses of the participants in the study confirmed that to some extent certain services are rendered to patients throughout the different stages of the illness.

According to the treatment and care model (Chapter 2, 35) services for voluntary counselling and testing (VCT) should be made available at the asymptomatic stage. According to prison policy all offenders have access to this whilst in prison. The study confirmed that the respondents received VCT services.

From the records it can be concluded that all of the respondents had access to medical services and care at all stages of the illness. The seven respondents in this study received the services of a medical doctor during the end phase of the treatment and care model, which is the phase they were at. Although nursing services were provided whilst the patients were in hospital, there were mixed reactions from the respondents about the quality of this care. The study revealed that nurses did not fulfill the role of palliative nursing as reflected in theory (Taylor, Glass et al, 1997: 253).

During the progression of the illness some of the respondents were treated for opportunistic infections such as tuberculosis. However there were no services of medical specialists at the prison hospital at Durban Management Area. The study revealed that during the course of the illness two of the respondents had attended provincial hospitals for specialist services in the form of X-Rays. The respondents were dissatisfied with this process of referrals and access to specialist care. The responses of the offender patients could reflect a poor understanding of palliative care, which they perceived as second- class care, as they still believed that there was hope for recovery.

From discussions with the staff it was ascertained that the Department of Correctional Services does not deny patients the right to consult with their private doctors. In this study none of the respondents had the financial means to do so.



The issue of food and nutrition is an important element in all stages of the HIV and AIDS model of treatment and care. The majority of participants complained about the food served at the hospital. The study revealed that the diet plan in prisons is compiled by a dietician and is in line with the guidelines provided by the Department of Health. The dissatisfaction might thus be linked to taste and difficulties experienced in the serving of the meals rather than the nutritional content. This could reflect a poor understanding by the offender- patients about the nutritional value of the foods on the menu. It is encouraging that the Department of Correctional Services had taken note of the dissatisfaction expressed by offender- patients through the complaints and requests process and now have plans to introduce meals for terminally ill patients that will facilitate more humane means of chewing and swallowing, thus making the feeding process easier.

The family and children of the respondents did not receive support or counselling as required by the principles of palliative care. The results of this study thus exposed a gap in services in terms of support for the family. The family was, however, recognized as an important support system to the terminally ill offender-patient. This was evident in the effort in ensuring the transferring of patients to prisons closer to their homes. The offender-patients interviewed appreciated the contact and support they had with their families. Provision was also made to allow more visits than is usually available to other prisoners. The respondents were also able to use this opportunity to address unfinished business with their families, which served to alleviate anxiety.

According to the Canadian Palliative Care Association (1996: 16 –17) the practice of palliative care principles requires that patients and family members are informed about the disease, potential treatments and outcomes, appropriate resources and options available to enable them to make informed decisions about the patient's care and treatment. The study revealed that neither patient nor family members were consulted about or involved in the treatment and care services offered and this was identified as a visible gap in service delivery. The success of palliative care depends on effective communication and relationship building between the patient, family and caregivers.

As discussed in the literature review palliative care cannot be practiced within a framework of authoritative hierarchy where the family and patient are dictated to by caregivers, (Fox in O'Neill & Selwyn et al, 2003:18), as happens within the correctional environment.

The Department of Correctional Services placed a lot of emphasis on spiritual and religious support of prisoners at all stages of the illness. Studies (Puchalski, 2003: 290) have shown that people find great comfort in engaging with religious leaders during periods of chronic illness, even if they were not actively involved in religion before they became ill. This was confirmed by the results of this study. The respondents in the study were dissatisfied with only attending church services and wanted individual pastoral counselling, which was not available to them. They might have had a need to explore issues around the meaning of their lives, the fear of death and the realization that they will be separated from their loved ones.

The majority of participants believed in the benefits of traditional healing. The policy of the Department of Correctional Services (B-Order, Ch.3, S.25) made provision for consultations with traditional healers. However traditional medicine was not allowed into hospital for security reasons. The respondents felt cheated by this perceived contradiction in the policy, which limited their access to a right given to them.

The results of this study revealed that there was a gap in the provision of leisure and recreation services to offender-patients who were terminally ill and hospitalized. The respondents complained that they were deprived of these privileges that were available to offenders in the general cells.

This resulted in them being bored and unoccupied and they felt discriminated against compared to the offenders in the general prison population.

One of the contextual adjustments of implementing the principles and philosophy of palliative care in prison is the system of complaints and requests. Through this process an attempt was made to allow the prisoner a certain amount of control and choice in his life. Although officials visited the hospital daily as dictated by policy the respondents complained that no feedback was received concerning the complaint or request that was registered. This lack of action made the patients feel frustrated, powerless and marginalized. Ensuring implementation of policy is a challenge facing the management of correctional facilities. The researcher is of the opinion that members of the interdisciplinary team at the Department of Correctional Services can play an active advocacy and lobbying role to ensure conditions that make the patients as comfortable as possible. It is heartening to note that the Department of Correctional Services granted permission for this study to be undertaken and for the “voice of the offender” to be heard. This indicates commitment to openness and transparency and highlights their commitment to making changes in the best interests of the offenders.

Correctional Services legislation (Act No 111, 1998: S.79) makes provision for any patient in the terminal stages of a disease to be considered for medical release to enable him/her to die a consolatory and dignified death. Review of literature has confirmed that this is a practice that is used by correctional facilities internationally (MacDougall, 1998:12). The study revealed that this service was available to the respondents in the study.

The doctor, nurse and social worker worked closely together when considering a patient for placement on medical grounds.

Careful consideration was also given to the capability of the family in caring for the offender-patient, especially since all of them came from poverty stricken circumstances. This indicated that the prison authorities attempted to ensure the dignity and best care for the prisoner. However problems in the administration of the system often caused delays in finalizing the applications for medical release.

Frohlich (2003:24) as discussed in Chapter 2, 50 states that volunteers form an integral part of the integrated palliative care service delivery team. Securing the services of volunteers from the community to work within a correctional setting is made difficult by strict security restrictions. The study revealed that sentenced offenders from the general cells worked as volunteers at the hospital. This illustrates an attempt by the Department of Correctional Services to make services in prison equivalent to services offered in communities. This conforms to the World Health Organization's guide-lines as discussed in Chapter 2, 27. The services of these offender-volunteers were formalized under the organization called the AIDS Control Committee (ACC). The roles and functions of this committee were governed by the draft policy on Correctional Centre Based Care: Offenders as Volunteer Care Givers. It is interesting to note that these volunteers extended beyond merely physically attending to patients but also to interventions that targeted the prison system. However, focus group discussions with the ACC revealed that these offenders were dissatisfied with the support they received from the prison management in implementing their roles. Also, the offender-patients expressed some dissatisfaction about the quality of the care they received from the offender-volunteers.

The philosophy of palliative care has indicated that patients and families experience a totality of illness with its varying dimensions, that is, medical, social, spiritual and psychological dimensions (Canadian Palliative Care Association, 1995:16). Thus, the services of an interdisciplinary team is required to meet the holistic needs of the patients. The team in prison comprised the medical doctor, nurse, social worker, spiritual worker, psychologist and custodial official. The study revealed, however, that the patients had regular contact with the doctor, nurse and spiritual worker only.

Whilst in the prison hospital, contacts with the social worker were only for purposes of investigations into compassionate release applications. According to literature (Kutzen, 2003: 49) the role of the social worker in palliative care is to help the patient and family deal with the personal and social problems of illness, disability and impending death, and to provide survivor skill-building and support. The limited role of the social worker is viewed as a serious gap in service delivery. There were no contacts with the psychologist, although both the prison psychologist and patients felt this service was necessary. The lack of access to the services of these professionals denied the patients the opportunity of dealing with their impending premature deaths as well as remorse for the crimes committed.

It was noted that these professionals did not work as a team in managing individual cases, except in the instances of compassionate release applications. This inability of team members to work together within an interdisciplinary context went against the principles and philosophy of palliative care and needs attention.

The absence of an occupational therapist on the staff establishment at the prison hospital was noted, as they form an important team member in the integrated curative care/palliative care model discussed in (Chapter 2, 50). The offender-patients themselves recognized the need for a physiotherapist on the interdisciplinary team. Physiotherapists are an integral part of the integrated palliative care team as advancing disease causes changes in the body that hinders everyday normal living. However it was heartening to observe that the patients had easy access to a range of medical assistance devices, for example, crutches, medical trolleys, walking sticks and wheel chairs. According to Fox in O'Neill & Selwyn et al (2003:18) one of the goals of palliative care is the restoration of functional capacity to ensure that the dignity of the patient is not impaired. The availability of the assistance devices thus enabled the patients to maintain their independence and dignity.

Culturally relevant services were emphasized by prison policy throughout the progression of the illness. Offender-patients were allowed religious leaders of their own faith and as mentioned previously consultations with traditional healers were permitted.

Finally the study revealed that anti retroviral therapy was not provided, and protection from stigma and discrimination, which are seen as vital services during the progression of the HIV/AIDS illness, was not totally possible within the correctional environment.

**Recommendations by researcher based on the above:**

- Educational programs are necessary to empower offender patients about palliative care and healthy living, for example, the role of diet and importance of compliance to medication.
- There is a need for effective teamwork and proper case management by the team. The multi-disciplinary team needs to ensure a more integrated and interdisciplinary approach to the provision of services to the patients to ensure that the total needs of patients are met in a coordinated manner.
- There is a need for increased access to social work, psychologist and specialist medical care services for AIDS patients in the final stages of the illness.
- Lobbying and advocacy by social workers is necessary to ensure human rights are maintained.
- Spiritual assessments need to be undertaken to ensure that these services meet the needs of patients.
- Evaluation / satisfaction studies need to be undertaken to determine the effectiveness of the offender volunteer caregiver programme.
- Feedback system for requests and complaints needs to be enforced whilst offender-patient is in the hospital.
- Introduction of leisure activities, and possibly the arrangements for an occupational therapist to be part of the team.

### **4.3 Challenges In Providing Palliative Care Services Within A Correctional Context**

In this study many challenges to providing palliative care services within a correctional context were noted.

According to the philosophy of palliative care (Canadian Palliative Care Association, 1995:16) palliative care starts at the time of diagnosis and becomes more intensive as treatment changes to symptom management, support and preparation for death. The results of this study showed that the continuum of care and services was at times difficult to implement in a correctional setting as four of the respondents had to be transferred between prisons. Transfers were necessary in cases where the respondents were diagnosed with HIV/ AIDS whilst awaiting trial and were subsequently sentenced to different prisons. Transfers also took place to ensure that offender-patients were as close to their families as possible, which is a stipulation in the Correctional Services Act, No 111 of 1998. However, in this study the perusal of records showed no evidence of continuity of care in the form of a coordinated, continuous plan of care from admission to bereavement in cases where offender-patients were transferred between prisons. This is one of the key elements in providing palliative care services according to the Canadian Palliative Care Association (1996: 16-17) and is a challenge to implement within a correctional setting.

Another challenge is that there are increasing numbers of offenders who were already ill with HIV/AIDS when sentenced. This places a serious burden on the Department of Correctional Services, as prisons do not have adequate health care facilities and resources. It is difficult to provide intense and specialized care needed by terminally ill patients in prisons.

Overcrowding is a serious problem and staff stated that admission of offenders needing intense, specialized care placed an extra burden on them. Overcrowding impacts negatively on the provision of qualitative and quantitative services to

offenders. It also results in additional costs within the budget of the Department of Correctional Services.

In this study four respondents were admitted to the prison hospital in the year that they were sentenced. Such sentencing defeated one of the primary aims of imprisonment, which is rehabilitation. The rehabilitation process could not be undertaken as they were admitted to the prison hospital shortly after sentencing. What are the legal and social implications of alternate sentencing for persons who are ill with HIV and AIDS and have committed serious crimes? This is a challenge that confronts the entire integrated justice system in South Africa.

The policy and processes for the medical release of terminally ill offenders is in place and might alleviate the above-mentioned overcrowding problem to a limited extent. Staff reported that the challenge lies in managing this process in the shortest possible time period, considering that the patients who qualify for this service are terminally ill and could die in prison if the process is prolonged. It might be necessary for clear time frames to be set for the process to be concluded and a monitoring framework created to ensure compliance with the prescribed time frames. Regular monitoring after placement on medical parole is also necessary to ensure proper care of the patient by caregivers and to ensure a prevention of re-offending in the event of recovery to a reasonably healthy state.

Other challenges that emerged from the focus group discussions were the difficulties of allowing traditional medicine in prisons. Some of these difficulties revolved around the control of the administration of traditional medicine. Various ethical and practical dilemmas were raised about the possibility of complications arising with patients who may opt to utilize both traditional and western medicine at the same time. According to the Oxford Textbook of Palliative Medicine (2003: 3) palliative care promotes sensitivity to personal, cultural and religious values, beliefs and practices. There is thus a need for further deliberation in this regard as the rights of patients to traditional medicine has to be balanced against the concerns mentioned above.



Although there was some evidence of teamwork the study also revealed that case-management by the team posed a challenge. The quality of services was negatively affected by the lack of co-ordination of services by the multi-disciplinary team. A further challenge that is linked to the lack of co-ordination of services is the lack of specific training in palliative care. Training will ensure the team understands the necessity of working together in managing a case and in involving family members in case management. Staff shortages brought about by vacant posts and overcrowding is a major challenge that impacts on the effective coordination of services.

One way to overcome the above challenge was by forming partnerships with non-governmental and community based organizations that have specific skills and experience in the provision of palliative care services. According to Thigpen and Hunter (1998: 4) in the literature review a partnership with hospices has been successful in United States prisons.

The challenge of vacant posts and overcrowding could be addressed by the creation of palliative care centers in certain prisons. Literature review (Crowther, Rochford, et al, 2002: 3) had also suggested that it might be possible for some prison hospitals to be designated regionally as palliative centres. These centers could be adequately resourced to meet the total needs of the terminally ill patients. However patients may be reluctant to move to palliative centers as it could be far from families and it will separate them from familiar inmate support at their current facilities.

The provision of health care services in a correctional setting is a challenge as it is practiced in a secondary setting where the primary focus is on detention, custody and security. Additionally the study also revealed that the professional staff, who were mostly women, expressed fear for their personal safety. This could be regarded as a primary work related stressor and needs the attention of management.

The issue of security of the community was also cited as a challenge by staff who stated that it restricted referrals for specialist care to provincial hospitals. Related to this is the challenge of finding a coordinated cost-effective specialist service between the provincial hospitals and the prison hospital. The challenge is to find a cost effective way of equipping the prison hospital to cater for a small number of offender-patients who would actually need or use these sophisticated services. A further option to be considered is to employ certain categories of specialists on a session basis who will visit the patients on a regular basis. However, the success of this option will depend on the costs that will be involved and the availability of these specialists.

The roller-coaster nature of the AIDS disease poses a further challenge in this area, where patients may progress from being close to death to recovery to a reasonably healthy former state. The challenge here is in two areas, namely, hesitancy in immediately releasing this patient on medical grounds as he/she could recover sufficiently and commit further crimes, and secondly, it takes its toll on both the patient and caregiver in that the patient may be prepared for dying only to recover and go through the whole trauma again later.

This study revealed that the prison culture poses an obstacle to the provision of qualitative services. The institutionalized correctional environment demands survival of the fittest and strongest, which is often in conflict with the requirements of the treatment and care programme.

The provision of anti-retroviral therapy is a challenge currently being experienced in communities. It is even more of a challenge in prisons where no clear guidelines exist for its administration, nor are supplies of the drug available. Correctional facilities are also not accredited by the Department of Health to provide anti-retroviral therapy to patients. The World Health Organization's equivalence rule also places a tremendous challenge to correctional facilities.

The administration of medication remains a challenge within the correctional environment because of confidentiality and privacy issues, which leads to non-compliance.

Care for caregivers was non-existent in prison, but was viewed as being essential, as the unpredictable course of the HIV/AIDS disease and the death of young patients can create significant stress and burden for caregivers. The nurses and offender-volunteers had recognized the need for care for caregivers and lamented its absence. The introduction of support structures and de-briefing sessions for prison caregivers is a challenge that is currently facing management and is something that requires urgent attention.

It can be seen from the above that some palliative care services are provided within the confines of the prison hospital. There are, however, constraints experienced by virtue of the context in which the service is provided, by policy constraints, by overcrowded conditions, by staffing shortages and lack of specific training in the provision of palliative care services.

## **4.4 Recommendations**

### **4.4.1 Recommendations Proposed By Research Participants**

The participants and staff made recommendations around improving palliative care services at the prison hospital.

Both patients and staff recommended that the vacant posts at Durban Management Area should be filled as a matter of urgency, particularly with regards to nursing staff. The participants recommended that nursing assistants should be appointed to supplement the full complement of the nursing posts because of the dire need for nursing care. In this regard the nurse in the group further recommended that the posts of auxiliary nurses be re-instated as their appointment will enable the registered nurses to focus on clinical patient care rather than auxiliary services like bathing, feeding and turning bed-ridden patients.

Another recommendation from staff was the employment of an aggressive retention strategy to prevent the exodus of staff. The nurses also strongly recommended that the promotion policy should be re-visited as the lack of promotional opportunities served to de-motivate them, which also contributed to resignations. However, the filling of posts and the adoption of a retention strategy should be simultaneous actions or else the brain drain will negate the benefits of having all the posts filled.

The need for support from officials and management in implementing the volunteer offender program was highlighted in the focus group discussion with the AIDS Control Committee. It will enable the offender volunteers to work within a recognized framework and will serve to protect their human rights. The finalization of the draft policy on correctional center based care should be treated with urgency.

The professional staff recommended the establishment of a creative balance between the requirements for the safe custody of offenders and the escorting of patients to external hospitals for specialist care. They were of the opinion that the needs of offenders should not be compromised. There was also great concern over the safety of female staff. They recommended that measures be put in place to ensure their safety, as constant fear for personal safety impacts on service delivery.

In particular the nurse recommended that clear internal guidelines and policy should be established for the provision of antiretroviral therapy. There was a strong feeling also that the policy on traditional healing needs to be revised as it created conflict with the needs of offenders.

Lastly, it was recommended that the medical release policy should be more specific. The staff recommended that clear time-frames for the conclusion of the medical placement process should be included to avoid patients dying before their applications are processed.

#### **4.4.2 Recommendations by Researcher**

The researcher submits the following recommendations based on the above challenges and recommendations made by the participants in the study:

- A concerted and sustained strategy to reduce overcrowding is necessary in conjunction with partners in the integrated justice system, since the Departments of Correctional Services, Justice and Police Services have to agree on a combined strategy. Reduction in overcrowding will assist in improving general prison health conditions as well as ensuring the provision of quality health care services to inmates in less crowded conditions.
- A well-developed human resource strategy is required which will ensure the creation of posts as well as the speedy filling of vacant posts. This strategy should include a retention component and a personnel wellness program, which will also address the issues of burnout and support for staff.
- The Department of Correctional Services needs to develop an integrated model of care which will include all relevant role-players, and will employ creativity and innovation in taking cognizance of security and the holistic health needs of patients.
- The staff needs to be specially trained in providing palliative care services and an effort needs to be made to link up with external resources in communities who have the necessary expertise in the field of palliative care to undertake this training and provide ongoing support to staff.
- The caregivers (staff and offender volunteers) need access to support services and de-briefing sessions to prevent burnout and de-motivation due to the nature of their work and the environment, which has many stressors.
- The White Paper on Correctional Services promotes societal responsibility in corrections. It is imperative that the Department of Correctional Services establishes meaningful relationships with external organizations, for example, the hospice movement, in order to provide an effective palliative care service to offender-patients in partnership with these organizations.

- Community volunteers could be utilized to provide companionship and support to the terminally ill patients, after undergoing a vetting process to satisfy security clearance requirements. Family members could also assist in caring for their loved ones under the supervision of the nurse.
- The patient and family should be consulted about the treatment options available and provided with the opportunity to make informed decisions about treatment and care, in line with the philosophy of palliative care.
- There should be closer monitoring, supervision and evaluating of the activities of the offender volunteers, which will ensure support for the latter whilst also protecting the interests of the patients and offender-volunteers.
- The placement policy should be amended to include minimum time frames for the processing of applications for placement on medical grounds to ensure the speedy release of patients who qualify.
- The judiciary needs to consider the utilization of community- based sentences for offenders who are diagnosed with terminal illnesses.

#### **4.4.3 Recommendations For Future Research**

As indicated in this report there has been no study conducted to determine the prevalence of HIV and AIDS in correctional centers in South Africa. It is thus recommended that a prevalence study be conducted as the results can assist in determining prevention and treatment strategies in the short, medium and long term.

Other possible related research areas include:

- Alternate sentencing for people who have HIV/AIDS when entering the correctional service system
- Models for care facilities for people who are terminally ill with AIDS
- Medical parole for patients who are terminally ill with HIV/AIDS due to the roller-coaster nature of the illness
- HIV and AIDS stigma related issues in correctional centres
- Development and evaluation of a mentorship/support program for offenders who render correctional center based care voluntarily.

## **4.5 Conclusion**

It can be concluded that the Department of Correctional Services has introduced legislation to protect the rights of prisoners who are infected with HIV/AIDS.

Internal policy guidelines have been adopted and constantly being drafted to improve care services for offender patients. The results of this study illustrated that some elements of palliative care have been put in place at Durban

Management Area and in particular at the prison hospital at Medium B Correctional Centre. However it is difficult to provide palliative care services within the context and constraints imposed by a correctional setting. To a large extent correctional facilities worldwide are grappling with similar challenges.

Attempts to overcome these challenges and some innovations have been adopted by the Department of Correctional Services and in particular at Durban Management Area.

## BIBLIOGRAPHY

- Academy for Educational Development (2001)  
[www.healthstrategies.org/Publications/publications.htm](http://www.healthstrategies.org/Publications/publications.htm): Accessed on 10/11/2004.
- AIDS Status Not Relevant To Length of Prison Sentence (2001) AIDS policy and Law: <http://www.aegis.com/news/ads/2001/ADO11733.html>; Accessed on 31/01/05.
- Alexander, C S. Schietinger, H. (2003) **Special Populations**. Second Edition. London: Oxford University Press.
- Alter-AIDS Complementary Medicine for a Healthier Community (2004)  
Advantages of Traditional African Healing:  
<http://www.writing.uct.ac.za/ELL319F/students2001/deborah/website/advantages.htm>: Accessed on 07/12/2004.
- Avert.Org (2004) HIV & AIDS In Africa: <http://www.avert.org/aafrica.htm>: Accessed on 27/10/2004.
- Avert.Org (2005) South Africa, HIV/AIDS Statistics:  
<http://www.avert.org/safricastats.htm>: Accessed on 12/01/05.
- Avert.Org (2004) World HIV & AIDS Statistics:  
<http://www.avert.org/worldstats.htm>: Accessed on 18/04/2005.
- Avert.Org (2004) Treatment and Care: <http://www.avert.org/treatmentandcare.htm>: Accessed on 18/04/2005.
- Beaver, K. Luker, K. Woods, S. (1999) **Conducting Research with the Terminally Ill: Challenges and Considerations**: International Journal of Palliative Nursing: Vol.5. No.2, 13-17
- Beresford, L. (2004) **Expanding Horizons: Serving Dying Patients in Correctional Facilities**: Vol.15. No.4, 1, 4-5.
- Berry C L. (2002) **The Need For Nurses Working In Hospitals To Be Educated in Palliative Nursing Care**: Pietermaritzburg: Printed by Msunduzi Hospice.
- Blacher, R S. (2002) **On Death and Dying**: A Primer for Medical Students and House Officers: <http://www.lifethreat.org/OnD&D.htm>: Accessed on 27/10/2004.
- Bless, C. Higson-Smith, C. (2000) **Fundamentals of Social research Methods, An African Perspective**. Third Edition. Cape Town: Juta Education (Pty) Ltd.



Blumberg, M. (1990) **AIDS: The Impact on the Criminal Justice System**: Columbus, Ohio: Merrill Publishing Company.

Braun, M M. Truman, B I. Maguire, B. DiFerdinando, G T. Wormser, G. Broaddus, R. Morse, D L. (1989) **Increasing incidence of Tuberculosis in a Prison Inmate population: Association with HIV Infection**: Journal of American Medical Association, 393-367.

Bryne, M. (2002) **Spirituality in Palliative Care: What language Do we Need?** International Journal of Palliative Nursing: Vol.8. No. 2, 67-73.

Byock, I R. (2002) Dying Well in Corrections: Why Should We Care? Journal of Correctional Health Care, 2002. <http://www.dyingwell.com/jchc02.htm>: Accessed on 27/10/2004.

Canadian Palliative Care Association. (1995) **Palliative Care: Towards a Consensus in Standardised Principle of Practice**: Palliative Care Association: Toronto.

Carbone, D J. (2001) The Body: An AIDS and HIV Information Resource: **Under Lock and Key: Youth Under the Influence of HIV**: Vol.XIV. No. 5, 1-5.

Catterall, M. Cox, M. Greet, B. Sankey, J. Griffiths, G. (1998) **The Assessment and Audit of Spiritual Care**: International Journal of Palliative Nursing: Vol.4. No.4, 162-168.

Centres for Disease Control and Prevention (2001) [www.edc.gov/idu](http://www.edc.gov/idu): Accessed on 10/11/2004.

Chilver, K. (2002) **Should We Give Palliative Care to all Those That Need It?:** International Journal of Palliative Nursing: Vol.8. No.2, 75-77.

Cochrane, J. (2003) **The Experience of Uncertainty for Individuals with HIV/AIDS and the Palliative Care Paradigm**: International Journal of Palliative Nursing: Vol.9. No. 9, 382-387.

Color Wheel Pro- See Color Theory In Action (2004) <http://www.color-wheel-pro.com/color-meaning.html>: Accessed on 25/11/2004.

Correctional Services Act, No 11 of 1998: Government Printer: Pretoria

Crowther, K. Rochford, S. Richman, J. (2002) **Issues in Palliative Care The Elderly in Prison**: Vol.02/ Issue 10, 49-51.

Dean, R A. McClement S E. (2002) **Palliative Care Research: Methodological and Ethical Challenges**: International Journal of Palliative Nursing: Vol.8. No. 8, 376-380.

Department of Correctional Services internal policy guidelines (**B-Order**): Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Comprehensive Health Care Programme**: 2005: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Comprehensive Programme for HIV/AIDS**: 2005: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Concept Document on Rehabilitation**: 2004: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Conceptual Framework: Development and Care**: 2004: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Draft Comprehensive HIV and AIDS Programme for Offenders**: 2004: Pretoria. Printed by the Department of Correctional Services. Printed by the Department of Correctional Services.

Department of Correctional Services: Draft Policy: **Correctional Centre Based Care: Offenders as Volunteer Care Givers**: 2004: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Policy Document: Management Strategy for HIV/AIDS in Prisons**: 1996: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Policy Regarding HIV and AIDS in The Workplace**: 1999: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services: **Strategic Plan 2005/2006**: Pretoria. Printed by the Department of Correctional Services.

Department of Correctional Services (2005) **White Paper on Corrections**: Pretoria. Printed by the Department of Correctional Services.

Department of Health (1997) **Workshop to Develop Strategies for Care**: Directorates HIV/AIDS and STDs and Communicable Diseases: Pretoria. Printed by the Department of Health.

Department of Health (2001) **National Guideline On Home-Based Care & Community Based Care**: Pretoria. Printed by the Department of Health.

Department of Health (2002) **Integrated Community-based Home Care (ICHC) in South Africa: A Review of the Model Implemented by the Hospice Association of South Africa**: Pretoria. Printed by the Department of Health.

Department of Health (2003) **Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa**: Pretoria. Printed by the Department of Health.

Department of Public Service and Administration (2002) **Managing HIV/AIDS in the Workplace: A Guide for Government Departments**: Pretoria. Printed by the Department of Public Service and Administration.

De Vos, A S. Strydom, H. Fouche, C B. Delport, C S L. (2002) **Research at Grass Roots: For the Social Sciences and Human Service Professions**: Second Edition. Pretoria:Van Schaik Publishers.

Dorrington, R. Bradshaw, D. Budlender, D. (2002) **HIV/AIDS profile in the Provinces of South Africa: Indicators for 2002**: The Centre for Actuarial Research, Medical Research Council - The Burden of Disease Research Unit, The Actuarial Society of South Africa.

Doyle, D. Hanks, G. MacDonald, N. (1993) **Oxford Textbook Of Palliative Medicine**: Second Edition. Oxford : Oxford Medical Publications.

Engle, L. (1999) **It's a Crime! HIV Behind Bars**: Body Positive, Vol.X11. No.1, 1-5.

Fagan, J J: Judicial Inspectorate of Prisons: **Annual Report 2002/2003**: Formeset Printers: Cape Town.

Fagan, J J: Judicial Inspectorate of Prisons: **Annual Report 2003/2004**: Formeset Printers: Cape Town.

Fagan, J J. (2003) **OSFSA-Prisons Round Table: Deaths in Prisons: Trends Predicted for next 10-20 Years**, 1-4. <http://judicialinsp.pwv.gov.za>: Accessed on 26/11/2004.

Ferris, F D. Flannery, J S. McNeal, H B. Morissette, M R. Cameron, R. Bally, G A. (1995) **A Comprehensive Guide for the Care of Persons with HIV Disease: Module 4: Palliative Care**: Mount Sinai Hospital and Casey House Hospice, Toronto, Ontario: Kirkpatrick & Associates Printing Inc.

Frohlich, J. **Draft Guidelines for Community Home Based Care and Treatment - Care for People Living With AIDS**: Compiled for the Department of Health: Directorate: STDS and HIV/AIDS: CERSA, MRC, Pretoria.

Fuller, J G. (2001) **The Body: An AIDS and HIV Information Resource: Overcoming the Fear in Prison: The HAAP Experience**: Vol. XIV. No. 5, 1-7.

Govender, S. (2004) The Sunday Times, November 21 2004: **Vacancies in the Public Sector**, 5.

Goyer, K C. Salojee, Y. Richter, M. Hardy, C. (2003) **HIV/AIDS In Prison: Treatment, Intervention, and Reform: A Submission to the Jali Commission** on behalf of the AIDS Law Project and The Treatment Action Campaign, Johannesburg.

Goyer, K C. (2003) **HIV/AIDS In Prison: Problems, Policies and Potential**: Monograph 79.

Haggerty, F. (2000) **CRIA UPDATE: A Publication of the Community Research Initiative on AIDS: Incarcerated Populations & HIV**: Vol.9. No.3, 1-5.

Hammett, T M. Harmon, P. Maruschak, L M. (1996-1997 update) **HIV/AIDS, STDs, and TB in correctional facilities. Issues and Practices in Criminal Justice**, Washington (DC): U.S. Department of Justice, National Institute of Justice; July, 1999. NCJ 176344. [www.ncjrs.org/pd](http://www.ncjrs.org/pd): Accessed on 10/11/2004.

Hardman, M. (1995) **Masoyi Home Based Care Project**: Africa School of Missions: White River.

Harvey, E. (2002) **Rape In Prison: An Intervention by Rape Crisis at Pollsmoor Prison** by Rape Crisis in the Western Cape: Vol.11. No.2, Prison Transformation in South Africa: 4.

Heywood, M. (2001) **The HIV/AIDS Problem in Our Prisons: A Collective Social Responsibility: Report of the Proceedings of the 1<sup>st</sup> National Symposium of Correctional Services**, Pretoria.

HIV+ Prisons Report: **Tips for Prisoners**: Special Report, Number 6, January 2000, 1-2.

Hornby, A S. Cowie, A P. Gimson, A C. (1974) **Oxford Advanced Learner's Dictionary of Current English**: London: Oxford University Press.

Hospice Africa. (1995) **Pain and Symptom Management Control in the Terminal Cancer and AIDS Patient**: Hospice Africa, Uganda.

Hudson, P. (2003) **Focus Group Interviews: A Guide for Palliative Care Researchers and Clinicians**: International Journal of Palliative Nursing: Vol.9. No.5, 202-207.

Human Rights Watch Prison Project (2003): **HIV/AIDS In Prison**.  
<http://hrw.org/prisons/>

Hunt, J. Cobb, M. Keeley, V L. Ahmedzai, S H. (2003) **The Quality of Spiritual Care- Developing a Standard**: International Journal of Palliative Nursing: Vol.9. No.5, 208-214.

Jansen, L A. Johnston, B E. Sulmasy, D P. (2003) **Ethical Issues**: Second Edition. London: Oxford University Press.

Kenny, L J. (2003) **An Evaluation-based Model for Palliative Care Education: Making a Difference To Practice**: International Journal of Palliative Nursing: Vol.9. No.5, 189-194.

Kubler-Ross, E. (1993) **Questions and Answers on Death and Dying**: New York: MacMillian Publishing Co.

Kupers, T. (2001) **Rape and Prison Code**: Philadelphia: Temple University Press.

Kutzen, H S. (2003) **Facilitating the Transition to Home-Based and Hospice Care**: Second Edition. London: Oxford University Press.

Levy, D. (1997) The Body: An AIDS and HIV Information Resource: **Viewpoint – Alternative to Jail: Hope for Incarcerated PWAs** : Vol.XI. No.3, 1-3.

Lindlop, E. Beach, R. Read, S. (1997) **A Composite Model of Palliative Care for the UK**: International Journal of Palliative Nursing: Vol.3. No.5, 287-292.

Lucas, S. (2003) **Palliative Care: Issues and Challenges**, 1-3

Ludlow, J. (2000) The Body: An AIDS and HIV Information Resource: Positive Living: **HIV Community Spotlight: Survival in the “Free World”**: Los Angeles Task Team Force Helps Inmates with HIV/AIDS.

MacDougall, D S. (1998) The Body: An AIDS and HIV Information Resource: **HIV/AIDS Behind Bars: Incarceration provides a valuable opportunity to implement HIV/AIDS treatment and prevention strategies in a high-risk population**, 1-15, from the Journal of the International Association of Physicians in AIDS Care.

Mamopi Consultants & Associates (2003) **An Appreciation of the Impact of HIV/AIDS on Planning and Development in KwaZulu Natal**: Provincial Planning & Development Commission: e-mail-ppdc@tiga.kzntl.gov.za.

Marodi, L R. (2003) **The Constitutional Rights of Prisoners within the South African Criminal Justice System**: Department of Criminology: University of South Africa, Pretoria.

Maruschak, L M. (1999) HIV In Prisons and Jails. Washington (DC): U.S. Department of Justice, National Institute of Justice, Bureau of justice Statistics; July 2001. NCJ 187456. [www.ojp.usdoj.gov/bjs/abstract/hivpi99.htm](http://www.ojp.usdoj.gov/bjs/abstract/hivpi99.htm): Accessed on 10/11/2004.

McMurray, J. ((2002) The Body: An AIDS and HIV Information Resource: **Lawmakers Push Action to reduce Prison Rapes**, 1-2.

Mhlope, M. (2005) The Natal Witness: **Living Strong With AIDS**: 1 December 2005, 18.

National Policy on Testing for HIV (1999): Government Notice No 1479: Department of Health: Government Printer: Pretoria

National Prison Hospice Association. <http://www.npha.org/links2.html>: Accessed on 10/11/2004.

Nerenberg, R. (2002) The Body: An AIDS and HIV Information Resource: **HEPP** (HIV Education Prison Project): **Spotlight: Condoms in Correctional Settings**: Vol.5. Issue 1, 1-4.

Neser, J J. (2003) **Penitentiary Penology**: Second edition. Johannesburg: Lexicon Publishers.

O'Neill, J F. McKinney, M M. (2003) **Care for the Caregiver**: Second Edition. London: Oxford University Press.

O'Neill, J F. Selwyn, Barini-Garcia, M. (2003) **HIV and Palliative Care**: Second Edition. London: Oxford University Press.

O'Neill, J F. Selwyn, P A. Schietinger, H. (2003) **A Clinical Guide to Supportive and Palliative Care for HIV /AIDS**: Second Edition. London. Oxford University Press.

Pagliaro, L A. Pagliaro, A M. (1992) **Sentenced To Death? HIV infection and AIDS in Prisons- Current and Future Concerns**: Canadian Journal of Criminology, 201-214.

Payne, S. Haines, R. (2002) **The Contribution of Psychologists to Specialist Palliative Care**: International Journal of Palliative Nursing: Vol.8. No.8, 401-405.

Payne, S. (1998) **Depression in Palliative Care Patients: A Literature Review**: International Journal of Palliative Nursing: Vol.4. No.4, 184-190.

Perez, J H. (1997) **Body Positive: AIDS Behind Bars- We Should All Care:** Vol.X. No.1, 1-6.

Poss, S. (1982) **Towards Death and Dignity:** National Institute: Social Services Library No 41. London: George Allen & Unwin Ltd.

Presentation to the Portfolio Committee on Correctional Services: **HIV/AIDS Debate:** Cape Town (2002) 1-4.

Prison AIDS Deaths up by 750%. [iafrica.com](http://iafrica.com): Accessed on 24/05/2004.

Puchalski, C M. Sandoval, C. (2003) **Spiritual Care:** Second Edition. London: Oxford University Press.

Ratcliff, M. (2000) **Innovations in the End of Life Care: Dying Inside the Walls.** <http://www.2.edc.org/lastacts/achives/achives>: Accessed on 27/10/2004.

Reder, E A. (2003) **Grief and Bereavement:** A Clinical Guide to Supportive and Palliative Care for HIV /AIDS: Second Edition. London: Oxford University Press.

Rubin, A. & Babbie, E. (1997) **Research Methods for Social Work:** Third Edition. New York: Brooks Cole Publishing Company.

Sandoval, C. (2003) **Culture and Care:** A Clinical Guide to Supportive and Palliative Care for HIV /AIDS: Second Edition. London : Oxford University Press.

Sapa. (2004) Sowetan, March 16 2004: **Terminal Prisoner Freed:** Johannesburg, 8.

Sapa. (2004) The Natal Witness, March 16 2004: **Terminally Ill Prisoner To Be Freed:** Pietermaritzburg, 3.

Sapa. (2005) The Natal Witness, December 8: **Court Orders Release of Convicted Murderer:** Pietermaritzburg, 4.

Saunders, C. Baines, M. (1983) **Living With Dying: The Management of Terminal Illness:** Oxford : Oxford Medical Publications.

Stephenson, J. Woods, S. Scott, B. Meadway, J. (2000) **HIV-related Brain Impairment: From Palliative Care to Rehabilitation:** International Journal of Palliative Nursing: Vol.6. No.1, 6-11.

**Stop Prisoner Rape.** [info@spr.org](mailto:info@spr.org): Accessed on 26/06/2004.

Sykes, J B. (1982) **The Concise Oxford Dictionary of Current English: Based on the Oxford English Dictionary and its supplements:** Oxford: Clarendon Press

Taylor, B. Glass, N. McFarlane, J. Stirling, C. (1997) **Palliative Nurses' Perceptions of the Nature of Their Work**: International Journal of Palliative Nursing: Vol.3. No.5, 253-258.

The Body: **An AIDS and HIV Information Resource: Body Positive** (2001) Vol.XIV. No.9, Newsline, 1-2.

The Body: An AIDS and HIV Information Resource: **Lambda Legal Applauds Bill Requiring Comprehensive HIV Prevention Education in New York Prisons**: News Release April 18, 2002. [www.thebody.com/index.html](http://www.thebody.com/index.html). Accessed on 28/11/04.

The Body Positive: An AIDS and HIV Information Resource: **AIDS Action (2001) Policy Recommendations, HIV Prevention and Care for Incarcerated Populations**. [www.thebody.com/index.html](http://www.thebody.com/index.html). Accessed on 28/11/04.

The Body Positive: An AIDS and HIV Information Resource: **AIDS Action (2003) UNAIDS Report Focuses on HIV, TB in Prisons**. [www.thebody.com/index.html](http://www.thebody.com/index.html). Accessed on 28/11/04.

The Constitution of the Republic of South Africa, Act No 108 of 1996: Government Printer: Pretoria

The Grace Project: Promoting Compassionate End-Of-Life Care in Prisons and Jails (2004) Cocksackie Regional Medical Unit Hospice, New York. <http://www.graceprojects.org/graceprojects/coxsackie.htm>: Accessed on 10/09/2004.

The Grace Project: Promoting Compassionate End-Of-Life Care in Prisons and Jails (2004) McCain Correctional Hospital Hospice, North Carolina Department of Corrections. <http://www.graceprojects.org/graceprojects/mccain.htm>: Accessed on 10/09/2004.

The Criminal Procedure Act, No 50 of 1951: Government Printer: Pretoria

The National Library of Medicine's Specialized Information Services (2001) <http://sis.nlm.nih.gov/HIV/HIVPrison.html>: Accessed on 27/10/2004.

Thigpen, M L. Hunter, S M. (1998) Hospice and Palliative Care in Prisons: **Special Issue in Corrections**: U S Department of Justice: National Institute Of Corrections: Information Centre: Longmont, Colorado.

Timour, K. (2001) The Body: An AIDS and HIV Information Resource: **Collected Wisdom on Your First Steps Out of Prison**: Vol.XIV. No.5, 1-8.

Twycross, R. Lichter, I. (2003) **The Terminal Phase**: Oxford Textbook of Palliative Medicine: Second Edition. Oxford : Oxford Medical Publications.

UNAIDS Point Of View (1997) **Prisons and AIDS**: UNAIDS Best Practice Collection. <http://www.unaids.org>: Accessed on 27/10/2004.



UNAIDS Technical Update (2000): AIDS: Palliative Care. <http://www.unaids.org>: Accessed on 27/10/2004.

Urquhart, P. (1999) **Issues of Suffering In Palliative Care**: International Journal of Palliative Nursing: Vol.5. No.1, 35-39.

Van Dyk, A. (1999) **AIDS Care and Counselling**: First Edition. South Africa: Maskew Miller Longman.

Venter, Z. Chetty, K. (2004) Daily News, 16 March 2004: **Prisoner Can Die With Dignity, Precedent as Judge Frees Cancer Victim**: Durban, 3.

Watson, R E. Riceberg, J L. (2002) The Body: An AIDS and HIV Information Resource: CDC News Updates: **A Dangerous Gap on AIDS Care in Prison**, 1-2.

Wilford, T. (2001) **Developing Effective Palliative Care Within a Prison Setting**: International Journal of Palliative Nursing: Vol.7. No.11, 528-530.

Wilkinson, S. (2000) **Spiritual Recognition Within Palliative Care**: International Journal of Palliative Nursing: Vol.6. No.1, 4.

World Health Organization: **World Health Organization and UNAIDS unveil plan to get 3 million AIDS patients on Treatment by 2005**: Press Release 1 December 2003: Geneva.

World Health Organization. (2003) AIDS Epidemic Update: **Global AIDS Epidemic shows no sign of abating/ Highest number of HIV infections and deaths ever**: Location: WHO>WHO sites>HIV/AIDS.

World Health Organization **Guidelines on HIV Infection and AIDS in Prisons**: WHO/GPA/DIR/93.3.

World Health Organization (1991) Global Programme on AIDS: **Report of The World Health Organization/Commonwealth Secretariat Regional Workshop On HIV/AIDS Community-Based Care And Control**: Entebbe, Uganda.

World Health Organisation (1994) Global Programme on AIDS: **Provision of HIV/AIDS Care in Resource-Constrained Settings**: Report of a Meeting, Geneva, 21-23 September 1994.

## APPENDIX

Consent form : offender-patients..... A

Consent form : staff..... B

Consent form : Offender volunteer caregivers: Members of  
the AIDS Control Committee ..... C

## APPENDIX A

To all participants: Offender-patients

Dear Sir

**RE: RESEARCH: MASTERS DEGREE IN SOCIAL WORK: MINI  
DISSERTATION ENTITLED “ A Study Into palliative Care Services For  
Offenders With AIDS At Durban Management Area”**

I am a registered Social Work Masters student at the University of KwaZulu Natal, Westville campus. Currently I am in the process of undertaking research for my mini-dissertation. The research focuses on palliative care services for offenders with AIDS at the prison hospital at Medium B Correctional Centre, Durban Management Area. My university supervisor is Dr Neeta Gathiram from the Department of Social Work at the above university.

One of the objectives of the study is to determine what palliative care services are available for offenders who are ill with AIDS at the prison hospital and how offender-patients perceive the services that they receive. Correctional Officials who render services to the offender-patients at the hospital will also be involved in the research, for example, social workers, psychologists, chaplain, nurses and custodial officials, as I believe that their knowledge and input is vital to this research.

I will conduct a focus group interview to collect the necessary information from you. The group interview will last approximately two hours. All information that you provide will be treated in the strictest confidence.

The focus group will be conducted in the Social Work group room at Medium B Correctional Centre, on 17 November 2004 at 10:00.

Should you require clarity/further information about this study, or me, feel free to contact the National Director: HIV/AIDS, Mr Gustav Wilson at 012-3058108 or Dr Neeta Gathiram, University of KwaZulu Natal at 031-2607932.

I would like to take this opportunity to thank you for participating in this study.

Yours faithfully

Aneetha D. Moodley  
Researcher

Please print your name and sign to confirm your participation in this study:

Name : .....

Signature : .....

Date : .....

## APPENDIX B

**To all participants:** Custodial official, Social worker, Nurse, Chaplain, Psychologist: Medium B Correctional Centre, Durban Management Area.

**Focus Group:** Palliative Care Services for Offenders with AIDS at Durban Management Area

I hereby wish to invite you to voluntarily participate in a focus group discussion on palliative care services for offenders with AIDS at the prison hospital at Medium B Correctional Centre, Durban Management Area. Your knowledge of and familiarity with policies, procedures and practicalities relating to the provision of this service constitutes a valuable resource, which can assist in evaluating existing and formulating improved mechanisms aimed at enhancing the provision of palliative care services for the terminally ill in prisons.

A focus group is a qualitative method that allows the researcher to interview several people at the same time, on a particular topic. The focus group enables members of the group to share their experiences and to reach some kind of consensus about the topic of research ( Bless & Higson-Smith, 1995:113).

The aims and objectives of the study can be summarized as follows:

- To ascertain what palliative care services are available for offenders who are ill with AIDS at prison hospital at Medium B Correctional center.
- To assist with the formulation of a more focused policy, concerning the provision of palliative care services to offenders who are ill with AIDS and are possibly dying.
- To make a contribution to the professional body of knowledge on how to improve palliative care services to offenders, as this is an under-researched area.

The focus group will be conducted in the Social work group room at Medium B Correctional Centre, on 11 November 2004 at 10:00.

All information will be treated as confidential.

Your co-operation in this research project will be greatly appreciated.

Kindly sign this request as an indication that you voluntarily participate in this research.

.....  
Full Name

.....  
Signature

.....  
Date

Contact Details of Researcher

Name: Aneetha D Moodley

Home: 27 Cowens Crescent  
Boughton  
Pietermaritzburg  
3201  
033-3442847

Work: Eugene Marais Road  
Napierville  
Pietermaritzburg  
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Contact Details of University Supervisor

Dr N Gathiram  
Department of Social Work  
University of KwaZulu  
Westville Campus  
031-2607932

**To all participants:** Offender volunteer caregivers: Members of the AIDS Control Committee, Medium B Correctional Centre, Durban Management Area.

**Focus Group:** Palliative Care Services for Offenders with AIDS at Durban Management Area

I am a registered Social Work Masters student at the University of KwaZulu Natal, Westville campus. Currently I am in the process of undertaking research for my mini-dissertation. The research focuses on palliative care services for offenders with AIDS at the prison hospital at Medium B Correctional Centre, Durban Management Area. My university supervisor is Dr Neeta Gathiram from the Department of Social Work at the above university.

One of the objectives of the study is to determine what palliative care services are available for offenders who are ill with AIDS at the prison hospital and how offender-patients perceive the services that they receive. Correctional Officials who render services to the offender-patients at the hospital will also be involved in the research, for example, social workers, psychologists, chaplain, nurses and custodial officials, as I believe that their knowledge and input is vital to this research.

I will conduct a focus group interview with you. A focus group is a qualitative method that allows the researcher to interview several people at the same time, on a particular topic. The focus group enables members of the group to share their experiences and to reach some kind of consensus about the topic of research (Bless & Higson-Smith, 1995:113).

The focus group will be conducted in the Social work group room at Medium B Correctional Centre, on 13 November 2004 at 10:00.

All information will be treated as confidential.

Should you require clarity/further information about this study, or me, feel free to contact the National Director: HIV/AIDS, Mr Gustav Wilson at 012-3058108 or Dr Neeta Gathiram, University of KwaZulu Natal at 031-2607932.

I would like to take this opportunity to thank you for participating in this study.

Yours faithfully

Aneetha D. Moodley  
Researcher

Please print your name and sign to confirm your participation in this study:

Name : .....

Signature : .....

Date : .....